2021 General Meeting Report

Online ZOOM meeting, June 19nd

Participants:
Directors: Daniel Tanesse (CMT-France); Filippo Genovese (ACMT-Rete); Marco van der Linden (Spierziekten Nederland); Simon Bull (CMT-UK); Dany Maes (Spierziekten Vlaanderen); Arabela Acalinei (Neuro Move CMT).
Full Members: Maria Paola Cadeddu (AICMT); Silvia Kendler (CMT-Austria); Maria Luisa Perrero (Progetto Mitofusina2); Andreea Maria Szabo (CMT-Romania); Ingolf Pernice (Deutsche Gesellschaft für Muskelkranke)
Partners: Jana Popova (Eamda)
Guests: Marina Brocca (LexicaMente); Irina Dobre (Aggelos); Anita Töchterle and Gerfried Huber (CMT-Austria); Larisa Sheloukhova (Russia)

Welcome to the Participants
President welcomes everyone at the ECMTF's General Member Meeting, the third since the Federation's establishment in 2018 and the second online. The President introduces the founding members, the ECMTF Board, the new members, the delegates, and the guests.
The Federation currently includes:

- 11 Full Members
- 4 Associate Members
- 3 Partners (CMT-NET, EAMDA & GANGLION)

After verifying that the necessary quorum has been reached (eleven members present out of eleven voting members), we proceed with the approval of the 2020 General Meeting minutes which are unanimously approved.

2020 MORAL REPORT by the President

1/ European CMT Awareness Campaign:

Thanks to a grant of 120.000 € from Pharnext, our central realization in 2020 was again our European CMT Awareness Campaign, the fourth one. In October, it took place in 7 European countries: Belgium, France, Germany, Italy, Netherlands, Spain, and the UK. With an

extension in some other countries - Israël, Romania & China – with the help of our Associations Members.

The targets were: the general practitioners, the specialists and health professionals and the public. The digital campaign aimed at doctors tun very well in almost all the countries. The Google Adwords campaign, thanks to Google Grants, aimed mostly to the public, has been particularly successful in Belgium, Italy, the Netherlands and in the UK.

In general, the traffic on our website raised; the numbers of likes and followers on FB, Instagram, and Twitter augmented as well. The video with Estelle & Roselyne was a great success. The billboards in Paris and London subways have been very successful. A better success in Milan this year with streets' billboard advertisements.

We also had two ambassadors who built scientific solidity to the campaign messages, helping arise curiosity and change of posture for doctors, and giving specific information on the disease; they were:

- Pr Philippe de Normandie, Orthopedic surgeon at Raymond Poincaré Hospital, at Garches (France);
- Dr Francesco Ferraro, Head of Neuromotory Rehabilitation Facility, at Bozzolo (Italy).

The details of the 2020 CMT Awareness Campaign results were presented on the 10th of December by Irina Dobre - Aggelos - and are at your disposal.

2/ Participation in several meetings, most of them, unfortunately online:
- General Assembly & ePAGs Meeting EURORDIS, in May
- 10th European Conference on Rare Diseases, in May
- EFNA General Assembly, in May
- General Meeting of the ECMTF, in June
- PNS Meeting, in June
- EURO-NMD Meetings, in July
- eNMD 2020, in October
- EURORDIS ePAG Annual Workshop, in November
- EFNA Meeting "Interest Group on BMP", in November
- Working Conference of the EFNA, in November
- Meeting and General assembly of the EAMDA, in December
- Plus several meetings with Aggelos for the organization of our Awareness Campaign.

NB: Participating in scientific meetings is a chance to learn more about our illness and lobbying opportunities. We can meet the labs & companies that sponsor these events and the scientists. We make our Federation better known, store valuable contacts, and consolidate our ties with other associations.

3/ ECMTF Board Meetings:
By Skype every two months, their reports are distributed to all Members.

4/ Conclusions:
With now 18 Members (Full, Associate & Partners), we have strengthened the Federation, its visibility, and credibility.
We have maintained our close contacts with CMTA, HNF & the CMT Research Foundation, the three associations representing the American CMT patients, and we work together for the sake of the worldwide CMT community.
We are definitely the key interlocutor and partner in representing the European CMT patient associations and the patients themselves.
In Europe alone, we are considered spokespersons and advocates for more than half of the total number of European CMT patients (154.000 out of 300.000).
We are officially members of the three most important European organizations: EURORDIS, the European Organization for Rare Diseases, the EFNA (European Federation of Neurological Associations) & TREAT-NMD.
Last but not least, labs working on drugs for CMT are asking us for their studies and therapeutic trials, for example:

- Augustine Therapeutics, a Belgium lab;
- Applied Therapeutics, a US lab;
- Nervosave Therapeutics, a French lab;
- Orizon Genomics, a Spanish lab,
- Plus, of course, InFlectisBioscience and Pharnext, the French labs.

2020 FINANCIAL REPORT by the Treasurer
The Federation's financial documents were provided before the start of the meeting. The Treasurer goes through the papers. No further ambiguities. Our financial situation is healthy.

Comments, Questions and Votes 2020 Reports.
There were no questions from the assembly about the President's report and the Treasurer's report. The assembly unanimously adopted the reports. The reports are at your disposal.

DISCHARGE OF DIRECTORS:
The discharge of the Directors is adopted at the unanimity.

BOARD COMPOSITION:
The current Directors were elected in July 2018, in conjunction with the official publication of our Statute, for a term of three years. It is, therefore, necessary to vote for the renewal or extension of the offices. We held a vote, and all of the following board members have been unanimously re-elected to the Board one by one:

- Simon Bull
- Filippo Genovese
- Dany Maes
- Daniel Tanesse

- Marco van der Linden

Ingolf PERNICE candidacy to the board has been unanimously adopted.
The roles of the board members will be determined in the next board meeting.

ACTIVITIES OF THE FEDERATION:

1/ Outsourcing / service providers
Little reminder for our new Members.
In the absence of employees and even an office, and as we are all volunteers already overwhelmed with work and tasks in our national associations, we decided to outsource the execution and administration of our main activities. To do this, we got a grant from a laboratory and entrusted this mission to LexicaMente, Marina's company, the service provider you already know. LexicaMente's Service Agreement, as well as the monthly reports Marina provides to the Board, are at your disposal. In 2020 the company's activities covered a wide range of tasks: Publications on our FB pages and Website, organization and reporting of our meetings, accounting, administrative tasks, secretary, "welcome desk" by mail, sponsors research, etc.
We also use Aggelos' agency services, Irina Dobre's help, and skills to improve our site and create communication materials.

2/ Partners / suppliers:

Actual Partners:

- EURORDIS membership thanks to a financial aid which we receive every year to organize our annual GM;
- EFNA, which is an umbrella structure for us;
- TREAT NMD.

Potential Suppliers:

- We are negotiating with RPP Group & COMM SANTÉ, two structures that propose the following offer:
    - We present them with a project (e.g. extension of the Awareness Campaign to Eastern Europe, Organization of an European Congress on CMT);
    - They estimate the total cost (the realisation of the project + their fees + our estimate fees) and they take care of finding the funding. In case of failure there will be no costs for us.

2021 ACTIONS AND PROJECTS

1/ Irina Dobre's presentation (Aggelos agency) of the 2021 CMT Awareness Campaign
The Power Point presentation of the Campaign is at your disposal.

2/ 2021 Forecast budget
The Treasurer presents the 2021 forecast budget and financial situation.

3/ ECMTF consolidation:

-Extension: Since the beginning of the year, a new association (DGM) and a new federation (EAMDA) have joined the Federation as a member and partner. In the near future, we hope to see the creation of CMT-Russia to be able to welcome it as a member of the Federation.

-Participation in meetings concerning the CMT & the ECMTF:

- EFNA Annual Partners Meeting, January
- EURORDIS RARE 2030 Webinar, February
- PANDEMIA Webinar on COVID, 18 & 19 March
- EFNA General Assembly, April
- World Orphan Drug Congress, April
- ERN-Euro NMD, June
- HealthTech For Patient Session (the ECMTF President took part in this webinar as speaker), June
- EFNA Webinar, June

Participation in other meetings and webinars is already scheduled for the remainder of the year.

-Search for Sponsors

- LexicaMente has prospected all the labs more or less involved in the CMT domain.
- We finally succeeded to obtain the grant from InFlectisBioscience (5K€).
- And we successfully negotiated a grant from Augustine Therapeutics (6K€).
- Last but not least, we expect a grant from Applied Therapeutics.
- We usually prospect systematically the sponsors of the meetings in which we participate (but this was not possible this year, due to on-line system).

3/ Short term projects

- Realization of our 5th Awareness Campaign in October, with a budget of 75 K€.
- Obtaining again a budget for a next year awareness campaign, the sixth one, despite the fact those campaigns were originally planned for three years.

4/ Mid-term projects:

- To help existing associations – members of the Federation – become better known and more powerful (we don't forget that it's one of our main goals);
- To try to promote the creation of CMT PAGs where there are not (in Europe).
- To extend our Awareness Campaigns to the Eastern European.
- To organize our own European Congress**.**

Divers Questions

We have a small talk with Larisa Sheloukhova. She is a Russian PhD student at Okinawa Institute of Science and Technology. She has CMT1A, and her biological background helps her read up on CMT-related research and inform other CMTs in Russia about CMT-related activities. Since she started her blog back in July 2020, she has organized several webinars in Russian regarding nutrition, therapies being developed for CMT, and family planning (together with a geneticist).

After a short exchange between the participants, the General Meeting is closed.

The President
Daniel Tanesse

The General Secretary
Marco van der Linden