



2020 General Meeting Report

Online ZOOM meeting, June 13nd

Participants:

Directors: Daniel Tanesse (CMT-France 🇫🇷); Filippo Genovese (ACMT-Rete 🇮🇹); Marco van der Linden (Spierziekten Nederland 🇳🇱); Simon Bull (CMT-UK 🇬🇧); Dany Maes (Spierziekten Vlaanderen 🇧🇪).

Full Members: Maria Paola Cadeddu (AICMT 🇮🇹); Silvia Kendler (CMT-Austria 🇦🇹); Maria Luisa Perrero (Progetto Mitofusina2 🇮🇹); Andreea Maria Szabo (CMT-Romania 🇷🇴); Arabela Acalinei (Neuro Move CMT 🇷🇴);

Associate Members: Itzik Lev (CMT Israel 🇮🇱); Sheng Li (CMT China 🇨🇳); Michael Zhang (CMT China 🇨🇳)

Guests: Marina Brocca (LexicaMente 🇫🇷); Goce Kalcef (Ganglion Skopje Macedonia 🇲🇰); Anita and Geofry Toechterle (CMT-Austria 🇦🇹).

Welcome to the Participants

President welcomes everyone at the second ECMTF General Member's Meeting, since the Federation's establishment in 2018, and particularly the representatives of the recently joined countries. President introduces the founding members and the ECMTF Board, the new members, the delegates, and the guests.

2019 Moral Report by the President

1/ Thanks to a grant of from Pharnext, our main realization in 2019 was our fourth European CMT Awareness Campaign. The 2019 CMT Awareness Campaign took place during October in seven European countries: Belgium, France, Germany, Italy, Netherlands, Spain, and the UK. The targets were: general practitioners/ specialists and health professionals, the general public. The digital campaign aimed at doctor run very well in almost all the countries (except for Spain). The Google Adwords campaign, thanks to Google Grants, aimed mostly to the public, has been particularly successful in Italy, Belgium, Netherland, and the UK.

In general, the traffic on our websites increased; the number of likes and followers on FB, Instagram, and Twitter augmented. The billboards in Paris and London subways have been very successful. On the other hand, the advertising on-screen in the Milan station wasn't as satisfying as we would have liked. We had two ambassadors who built scientific solidity to the campaign messages, helping arise curiosity and change posture for doctors, and giving specific information on the disease.

Ambassadors:

- Philippe de Normandie – orthopedic surgeon at Raymond Poincaré Hospital
- Giuseppe Piscoquito – neurologist at IRCSS Fondazione Maugeri.

The 2019 CMT Awareness Campaign results were presented during the December meeting in Paris (by Irina – Aggelos) and are at disposal.

2/ Participation in several important meetings:

- eNMD Meeting in Nice, March (e-health in NeuroMuscular Diseases);
- Jornada CMT/ASEM in Madrid, April;
- General Assembly & ePAGs Meeting EURORDIS in Bucarest, May;
- ACMT-RETE General Assembly in Rimini, May;
- General Meeting of the ECMTF in Genoa, June;
- PNS Meeting in Genoa, June;
- Meeting of CMT-AUSTRIA in Bregenz, September;
- Meeting of the EFNA in Warsaw, October;
- Debriefing Meeting on our Awareness Campaign in Paris, December.

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The Federation's participation in scientific meetings is a chance to learn more on CMT, to lobby with labs and companies that sponsor the events, and with the scientists. It is useful to make the Federation better known, storing valuable contacts, and strengthening ties with other Associations.

3/ ECMTF Board Meetings:

- By Skype or Zoom every two months;
- Face to Face in Genoa (June 2019) and Paris (December 2019).

4/ Conclusions:

With now 15 Members (Full & Associate), we have reinforced our organization and consequently, our strong international visibility. We have close contacts with CMTA & HNF, the two associations representing the Americans CMT patients, and we work together for the sake of the worldwide CMT community. We are the key interlocutor and partner in representing the European CMT patient associations, and therefore the patients themselves. In Europe, we are considered spokespersons and advocates for more than half of the total number of European CMT patients.

We are officially members of the two most important European organizations: EFNA (European Federation of Neurological Associations), and EURORDIS (European Organization for Rare Diseases). Last but not least, labs working on drugs for CMT ask us for their studies and therapeutic trials.

2019 Financial Report by the Treasurer

Financial documents were provided at the start of the meeting. The Treasurer goes through the papers. No further ambiguities. Our financial situation is healthy.

At the creation of the Federation, we did not know that we had to pay VAT on the services received. Then doubts arose about the country to pay the VAT: France (20%) or Belgium (21%). We know, finally, we have to pay it in Belgium, and funds have been set aside in the budget for this purpose.

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Forecast 2020 presentation by the Treasurer

The forecast for 2020 is presented.

Comments, Questions and Votes 2019 Reports.

There were no questions from the assembly about the President's report and the Treasurer's report. The assembly unanimously adopted the reports.

Discharge of the 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, not necessary to vote for the renewal or extension of the offices. We have received candidacy for becoming Director of the board by Mrs. Arabela ACALINEI. She is President and Delegate of the Romanian Association Neuro-Move. The nomination of Arabela Acalinei is adopted at the unanimity. The new board consists of the following persons:

- President: Daniel Tanesse (CMT-France);
- Vice-President: Filippo Genovese (ACMT-Rete);
- Treasurer: Dany Maes (Spierziekten Vlaanderen);
- General Secretary: Marco van der Linden (Spierziekten Nederland);
- Board members without a specific role: Simon Bull (CMT-UK); Arabela Acalinei (Neuro-Move CMT).

ECMTF Internal organization / Services Providers:

In the absence of employees and even an office, and as the ECMTF board members are volunteers, we have outsourced the execution and administration of our main activities to be able to conduct good governance. We got a grant from a laboratory and entrusted this mission to LexicaMente. We receive a report on this every month; all these reports are at disposal.

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We also use another service provider: Aggelos company, which takes care of everything related to our annual CMT Awareness Campaign.

Actions and Projects 2020

1/ ECMTF and EPAGs associations consolidation

1.1/ Participation in meetings concerning the CMT and the ECMTF

- Participation in the EURORDIS' online 10th European Conference on Rare Diseases, in May;
- Participation in EFNA online General Meeting, in May;
- Participation in EFNA webinars;
- Participation in PNS online meeting (in June);
- Participation in the 1st EAMDA (European Alliance of NM Disorders Associations) online Conference on NMD, previously planned in Romania.

1.2/ Search for sponsors

We contacted several laboratories that research CMT, and we sent them the sponsorship file. This document was created for us by Aggelos, and it is available to all, you can request it to the secretary. The search for new sponsors is arduous. In most cases our requests were not answered, except for the two following labs with which we have excellent contacts:

- InFlectisBioscience, a French Lab' working on CMT1A & CMT1B;
- Sarepta Therapeutics, an American Lab' working on CMT1A.

We systematically prospect the sponsors of the meetings in which we participate.

To reach other kind of sponsors, Aggelos in preparing an "action plan".

We invite all Members to bring us their ideas, suggestions, and contacts of laboratories or research centers that could sponsor us. No need to contact them, the secretary can do it.

1.3/ Our main goal

To help existing associations -members of the Federation -become better known and more powerful. To try to promote the creation of CMT PAGs where there are not (in Europe).

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2/ Short Term Projects

2.1/ 4th CMT Awareness Campaign in October 2020 with a budget of 120K€.

For this campaign, there will be a permanent reference on the Federation's website (and thus to your sites), in addition to a specific website created on purpose. A presentation meeting will be held in Paris on 5th October, and all the members will receive an invitation to participate.

2.2/ To obtain a new budget for the next year CMT Awareness Campaign, the fifth one, despite the fact those campaigns were initially planned for three years.

3/ Mid Term Projects

3.1/ In the context of the EJP RD (European Joint Program in Rare Diseases), CMT-France and ACMT-Rete (both founding members of the Federation) support two proposals of study the CMT. The promoters of these studies applied to the EJP RD Call for Proposal 2020 (Pre-Clinical Research to develop effective therapies for rare diseases), and we will know, by the end of June, if they are accepted. The two studies are:

- "Hope4myelin", from a French-Italian-Spanish consortium led by InFlectisBioScience;
- "MyGenter," from a French-German-Italian consortium of researchers working on CMT Gene Therapy for CMT1A.

3.2/ New Belgium Laws for NPO

There are new laws concerning the Non-Profit Organizations in Belgium. They were presented to us during the EFNA General Meeting on 25th May. We will have to make changes to our Statute, before 2024, to comply with those new regulations.

4/ Long Term Project

To organize our own CMT Congress.

Divers Questions

1/ Filippo informs us of the results of a survey on how the Covid-19 affected CMT patients. Two hundred eighty patients from all over the world participated, allowing survey organizers, to obtain valuable information. Results will be shared after the publication is published. Greater involvement of European associations would have been desirable. Filippo encourages, in the interest of the associations and the patients they represent, to be more involved also during the awareness campaign.

2/ Marina (secretary) requests all the Member Associations to be more reactive to the Federation's posts on the Internet and 'tag' the Federation in their jobs. This mutual appeal will increase the visibility of both the Associations and the Federation.

3/ Maria Luisa talks about the setback that CMT research has suffered in Italy due to Covid-19, and the scarcity of alternative news. She asks what the situation is in other countries.

4/ Arabela talks about a CMT fitness program she participated, which can be useful for CMT patients. (<https://madeformotus.org>)

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

The President
Daniel Tanesse



The General Secretary
Marco van der Linden

