Notes GENERAL ASSEMBLY – June 22, 2019 – Genoa

Participants:

Directors: Daniel Tanesse (CMT-France); Filippo Genovese (ACMT-Rete); Marco van der Linden (Spierziekten Nederland);

Members: Maria Paola CADEDDU (AICMT); Silvia KENDLER (CMT-Austria); Luisa Perrero (Progetto Mitofusina2); Simona Marcu (CMT-Romania);

Guests: Arabela ACALINEI (Neuro Move CMT, Romanian Association); Marina Brocca for LexicaMente

Absent: Simon Bull (CMT-UK); Dany Maes (Spierziekten Vlaanderen); Andreea Maria SZABO (represented by her sister Simona MARCU);

Proxies: Simon Bull (CMT-UK); Dany Maes (Spierziekten Vlaanderen).

Welcome to the Participants

President welcomes everyone and in particular the representatives of the recently joined countries at the first General Members Meeting since the establishment of the federation in 2017.

President introduces the founding members and the ECMTF Board, the new members, the delegates and the guests.

2018 Moral Report by the President

- Publication of our statutes in August 2018 and opening of our bank account at Belfius Bank (Brussels).
- Awareness Campaign in October, thanks to a grant of 175.000 € from the Pharnext laboratory.
- Participation to several important meetings:

- ASNP Meeting in Roma, April;
- EFNA General Assembly in Lisboa, June;
- PNS Meeting in Baltimore, July;
- Meeting in Munich, December (to try to boost the creation of a CMT Association in Germany).

- ECMTF Board Meetings:
  - By Skype every month;
  - Face to Face in Paris, November

In one year only we have gained good international visibility and we have established ourselves as the key interlocutor and partner in representing the European CMT patient associations, and therefore the patients themselves.

The American associations, CMTA and HNF, asked for our collaboration, CMT-CHINA having found us on Google asked for our help, CMT-ISRAEL wishes to cooperate with us, etc...

Official representative organizations have applied for our membership (EFNA, EURORDIS).

Last but not least laboratories working on drugs for CMT are asking us for their studies and therapeutic trials.

2018 Financial Report by the Treasurer

Financial documents were provided at the start of the meeting.

The President goes through the documents due to the Treasurer's absence.

A number of questions are asked and explained. No further ambiguities.

Comments, Questions and Votes 2018 Reports.

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

Discharge of the Directors:

Unfortunately, Karen Butcher (ex CMT-UK Delegate) had to leave the Board. She was the General Secretary. The Board proposes the following changes: Simon Bull, new representative of CMT-UK, will be on the Board and Marco van der Linden (General Secretary ad interim) will

be nominated as General Secretary. The assembly voted unanimously for the inclusion of Simon Bull in the Board and Marco van der Linden as General Secretary.

New Organization of the Federation / Outsourcing of certain activities / Services Providers:

- Marina Brocca for LexicaMente performs the administrative work for the ECMTF. She is paid for this from the ECMTF budget;
- Irina Dobre for AGGELOS agency, brings us her skills and helps to improve our website and create communication materials;
- As an official EURORDIS member, the organization of this ECMTF General Meeting has been sponsored by them.

2019 = Actions

- ECMTF & ePAGs associations consolidation ;
- Participation in meetings concerning the CMT and the Federation:
  - SFNP/Paris on February;
  - e.NMD /Nice, on March (the President as a speaker);
  - Jornada Informativa CMT/Madrid on April;
  - G.M. EURORDIS/Bucarest on May;
  - G.M. ACMT-Rete/Rimini on May;
  - PNS Meeting/Genoa on June.

- Search for new sponsors. In 2019 we have one major sponsor. We need to ensure that this gets more. Daniel spoke before the PNS Meeting with Maria Burian, director of the UCB. (A biopharma company) We will continue to discuss a sponsorship with them.
- 3rd CMT Awareness Campaign in October with a budget of 200 K€. It will take place in the following European countries: Belgium, France, Germany, Italy, Nederland, Spain and UK. Pharnext chooses these countries and this is in line with the PXT3003 drug. We hope to be able to expand this campaign by 2020.

2019 = Projects

- To obtain a higher budget for next year awareness campaign;
- To organize our European Congress.

Projected Budget

The 2019 business plan is being discussed and approved by everyone

Divers Questions

- Some countries outside Europe want to support us, but they cannot become members, as they do not fall within Europe. Marco suggests setting up a separate membership and calling this "Friends of the ECMTF". These special members will not have voting rights in the general members meetings.
- CMT-Austria has its annual contact day on September 28. They would like to see Pharnext as a speaker.

Daniel Tanesse
President

Marco van der Linden
General Secretary