ECMTF General Meeting – 10/06/2023 – Paris

Present was:
The following delegates of the Federation's Member Associations

Daniel Tanesse – delegate from CMT France, Full Member, president of the Federation
Ingolf Pernice – delegate from the CMT Group in DGM Germany, Full Member, vice president of the Federation
Filippo Genovese – delegate from AICMT-Rete from Italy, Full Member, vice president of the Federation
Marco van der Linden – delegate from Spieziekten Nederland, Full Member, General Secretary of the Federation
Dany Maes – delegate from Spierziekten Vlaanderen, Full Member, Treasurer of the Federation
Arabela Acalinei – delegate from Neuro Move CMT in Bulgaria, Full Member, and EAMDA, member of the Federation Board
Simon Bull – delegate from CMT UK, Full Member – member of the Federation Board
Cadeddu Maria Paola – delegate from AICMT from Italy, Full Member
Perrero Luisa – delegate from Progetto Mitofusina2 from Italy, Full Member
Zsuzsanna Varga – delegate from WondefFlora & CMT from Hungary, Full Member Inbal Ben David – delegate from CMT Israel, Associate Member
Allison Moore – from HNF in the US, Associate Member
Susan Reudiger – delegate from CMT RF in the US, Associate Member
Katherine Forsey – delegate from CMTA in the US, Associate Member

The following persons were also present:
Alexandre Hoyau, Board Member of CMT France
Delia Hotea, secretary of Neuro Move CMT
Rita Dravucoz, co-founder of WonderFlora and CMT
Giovannella Porzio, from Progetto Mitofusina2
Lisa Raineke, from CMT Net
Grace Marie Bricalli, Board Member of the European ME Alliance
Brice Chapuis, Run for CMT project creator
Sandrine Frederick from Aggelos
Marina Brocca, secretary of the European CMT Federation

The General Meeting is declared open at 3.00 pm.

Welcome to the participants

The President welcomes the participants and the new members of the Federation.

- Zsuzsanna Varga, Delegate and President of WonderFlora & CMT Alapitvány, the new Hungarian CMT Association, and Rita DRÁVUCZ, Founder of the association;
- Katherine FORSEY, CRO, Delegate of the CMTA, the American Association created in 1983
- Allison MOORE, Delegate & Founder of the HNF, the American Association created in 2001
- Susan RUEDIGER, Co-Founder of the CMT Research Foundation, the American Association created in 2018

We wish a warm welcome to our new members!

Thanks to these new members, the Federation currently includes:
12 Full Members,
8 Associate Members,
3 Partners.

Quorum

10 Full Members of 12 are attending the Meeting (CMT Austria connected on Zoom, but due to technical problems, he had to leave the meeting; the Asociația Charcot Marie Tooth România did not connect and did not send the proxy). The General Secretary confirms that the quorum has been reached.

Approval of the minutes of the 2022 General Meeting

The 2022 General Meeting was held in Berlin on 18 June. The minutes were sent to all members on 13 July 2022. The minutes are approved unanimously.

2022 Activity Report

European CMT Awareness Campaign
Thanks to a new grant from Pharnext - 75.000 € - our central realization in 2022 was again our European CMT Awareness Campaign, the sixth one.
The project was designed and managed by Aggelos - one of our communications agencies - and was presented to us at our General Meeting in Berlin on June 18 last year.
As usual, the Campaign took place in October in 7 European countries:
Belgium, France, Germany, Italy, Netherlands, Spain, and the UK, with an extension to Romania, thanks to the help of our local Member associations.
The targets were General Practitioners, Specialists, Therapists and patients.
-The digital Awareness Campaign aimed at doctors went very well in most countries.
-The Google AdWords campaign was a great success, thanks to Google Grants, aimed primarily at the general public.
-In general, traffic on our websites increased; the number of likes and followers on FB, Instagram, and Twitter also rose.
-Details of the results of the 2022 CMT Awareness Campaign were presented to us on December 15 by Aggelos and are available to you.

1st European CMT Specialists Conference
This project - now a reality - took up much time last year and this year.
Daniel Tanesse and Ingolf Pernice were deeply engaged in every aspect of the organization: places to visit, guest lists to invite, the program to draw up, but also, above all, looking for sponsors. More than 50 potential sponsors have been contacted, many requests have been sent, a lot of documentation has been produced, and all this work has paid off. It's too early to say it was a success, but the fact remains: we did it, and we are very proud of it!

2022 Rare Disease Day
We participated in the international "Living with CMT Art Competition": Competitors had to submit artworks illustrating their living conditions.
There were under and over 16 years old categories and three prizes for each category. A jury of members of the participating associations (ECMTA, HNF, and the ECMTF) voted for the winners, who won Amazon vouchers offered by associations.
Participants in the competition came from all European countries, from the USA and India. The initiative was quite successful.
As you know, we launched the "Talk CMT" competition in cooperation with Socking Clumsy this year, but we will give you an account later.

Participation in meetings (some of them online)
Daniel Tanesse and Marina Brocca participated in

- The Annual Meeting of the SFNP (French Speaking Society of the Peripheral Nerve) in Paris in January;
- PACARARE & EJPRD (Meeting Franco-Italian on Rare Diseases) in Nice in March;
- PNS Meeting in Miami on May;
- CMTA STAR Advisory Board in Miami on May;
- CMTA Summit online in October;
- European Patient Forum (EPF) Boot Camp "Data Saves Lives" in Prague on October;
- Several meetings with Aggelos for the organization of our Awareness Campaign.

On her side, Arabela ACALINEI - our Ambassador - represented our Federation in two important meetings:

- The General Assembly of the EFNA (European Federation of Neurological Associations);
- The Conference of the European Alliance of Neuromuscular Disorders (EAMDA) - of which she was the organizer and is the President - and during which our 1st Vice-President - Filippo GENOVESE - presented the ECMTF.

Taking part in medical or scientific meetings is not only a chance to learn more about our condition, but it's also a lobbying opportunity: with the labs & companies who sponsor these events, with scientists - to make our Federation better known & to store valuable contacts - and to consolidate our links with other associations.
Last year's results included promises of financial support for our Conference and the participation of those who are now our new American members.

ECMTF Board Meetings
The Board met every two months via Zoom, and all the meeting minutes (six) were made available to all Members. All meetings are recorded.

Conclusions
With now 23 Members (Full, Associate & Partners), we have continued to strengthen the Federation, its visibility, and its credibility.
We have reinforced our close contacts with CMTA, HNF, and the CMT Research Foundation, the three associations representing American CMT patients with whom we work in the interests of the worldwide CMT community.
We are now considered the single representative voice of all European CMT patient associations and, thus, the spokesperson and advocate for more than half of all European patients (162,000 out of 300,000), not counting our non-European members.
We are also official members of the three most important European organizations: EURORDIS, the European Organization for Rare Diseases, the EFNA (European Federation of Neurological Associations), and TREAT-NMD.
Finally, labs working on drugs for CMT call us for their studies and therapeutic trials, for example:
Augustine Tx, a Belgium Lab Applied
Tx, a US lab InFlectisBioscience, a
French lab Nervosave Tx, a French lab
Orizon Genomics, a Spanish lab
Pharnext, a French lab
Samsara Tx, a British lab (thanks to Arabela) Taysha
GTx, an American lab.
The General Secretary requests the approval of the 2022 Activity Report. The Report is approved unanimously.

2022 Financial Report
The Treasurer presents the 2022 Final Budget and Accounting.
The 2022 Final Budget shows a positive balance.
The 2022 Final Accounting is positive as well.
The documents had been made available previously and are attached to these minutes.
The General Secretary requests the approval of the 2022 Financial Report. The Report is approved unanimously.

Discharge of the Directors

The General Secretary proceeds to vote on the Discharge of the Directors.
The Discharge is approved unanimously.

Renewal of Mandate

Arabela Acalinei's term as a member of the Board of Directors is expiring.
At the request of the General Secretary, Arabela Acalinei expresses her re-candidacy.
The General Secretary votes on Arabela Acalinei's candidacy, which is approved unanimously.

New Treasurer Election

Dany Maes, the Treasurer of the Federation since its creation, tenders his resignation from this office while remaining a member of the Board.
We thank Dany for his fundamental contribution to the creation and consolidation of the Federation.
The new candidate for the position of Treasurer of the Federation is Simon Bull, whom we thank for his availability.
The General Secretary votes on Simon Bull's unanimously approved candidacy.

Election of new Board Members

According to the statute of the Federation, the Board of Directors can be composed of up to nine members. The Board consists of seven members, and two other Delegates from Full Members associations can present their candidacy.
No candidacy for a new Board Member was presented.

Actions and Projects 2023/2024

2023 Forecast Budget

The Treasurer presents the 2023 Budget and Accounting forecast.
Expenditures are expected to be higher than revenues; this is due to the lack of subsidies for the CMT Awareness Campaign and to the expenses of the General Meeting (which are only minimally covered by the EURODIS grant).
However, the reserves in the bank account guarantee the coverage of all expenses and bear witness to the financial solidity of the Federation.
The document presented contained a calculation error. An Errata Corrige will be attached to these minutes.

Extension and Consolidation of the Federation

This year new associations have joined the Federation:
WonderFlora and CMT (Hungary)
Spolecñost CMT (Czech Republic)
HNF (USA)
CMTA (USA)
CMTRF (USA)
Recently a new Chinese CMT association contacted us: Qianlixing CMT Mutual Aid House.

Participation in meetings concerning the CMT and/or the ECMTF

2023 Rare Disease Day Campaign

"Talk CMT" contest in cooperation with Socking Clumsy. We have invited the CMT community to send in some funny and motivational phrases to be printed on the socks produced by Socking Clumsy, a Lebanese company born from the initiative of Charbel Gemayel. The winners won socks from Socking Clumsy, the contest was quite successful.

2023 CMT Awareness Campaign

For 2023 we will not have the usual Pharnext grant for the Campaign (they have already funded the Conference). Despite this, we want to renew this annual appointment with the CMT community. We will use last year's saved and unspent money for the Campaign. In her following speech, Sandrine Frederick will show us Aggelos' proposal for the 2023 CMT Awareness Campaign.

Run for CMT

This project was born from the initiative of Brice Chapuis, who briefly explains his project. Brice is a French student following his university courses in Austria. Even though he has CMT, he is very confident with his body and can still run. To raise awareness of CMT, he decided to run the Vienna Marathon. Unfortunately, he got injured just before the race. Even if he could not participate in the competition, he succeeded in raising awareness of CMT through social media and with an interview for an influential Austrian newspaper. He didn't give up and is training for next year.
His initiative was associated with fundraising, and he donated 500 euros to the Federation.
A discussion follows among the delegates on the benefits for donors (tax benefits, i.e. the possibility of deducting the donation amount from taxes). These benefits are different for each European country.

First European CMT Specialists' Conference

The event was held on June 9 and 10 and has just ended (this GM is following closely).
Even if there would be no follow-up, all certainly agree that the openness and friendly atmosphere among all participants, the enthusiasm to get our work done, and the richness of information and valuable insights coming out of the workshops and plenaries as takeaways will already largely pay-off our investment in time, personal effort and money. There was also much networking and talk on cooperation among participants.
Indeed, the hundred scientists, clinicians, therapists, delegates of patient organizations, and industry representatives present at the Conference exchanged upon the newest developments in CMT sciences and forged the foundations and developed leading ideas for establishing a European CMT Research Association.
Several early-stage researchers had the opportunity to meet world-leading CMT specialists and present the audience posters on their running research projects. These fantastic posters rounded out the impression that we are facing a dynamic development of new approaches to CMT research

that opens thrilling perspectives for the industry and for the patients who urgently hope for therapy.
All speeches from the plenary sessions and workshops were recorded and will be edited and made available on the Federation website.
Now the question is: what's next?
It is advisable to create a consortium of researchers and experts because the presence of a strong organization facilitates the raising of funds.
We also want to organize webinars accessible to patients on research progress, trials, and other relevant topics, opinion papers, and articles to be published in different journals.
Katherine FORSEY suggests that the Conference outcomes could also be disseminated through white papers (an informal document more accessible to the general public).
Inbal Ben David proposes a business approach for future activities of the Federation by creating cross-functional teams to find solutions to the main issues relating to CMT (i.e. a treatment).
Choosing a method of action depends greatly on the goal of the organization. The Federation's ultimate goal is to find a treatment for CMT, but many steps must be taken on this pathway.
We must raise awareness, as CMT is a rare disease, and many essential decision-makers (politicians, companies, laboratories) don't know it and don't think this is a priority.
We must encourage research on CMT. The Conference aimed to help the communication of all the professional figures dealing with CMT by promoting the sharing of information and knowledge. This network of professionals is vital to support and encourage research on CMT.
If we want to walk our path successfully, it is essential to lobby from a strong position; the ECMTF represents the CMT Associations acting in Europe (and worldwide) as the sole European interlocutor in relation to other organizations (laboratories, institutional organizations).
These are realistic intermediate goals that we have largely achieved.
The final part of this discussion is consecrated to the pros and cons of creating a patient registry.
The workshop's aim on this topic was to find out the needs of researchers, what they need as critical information, and the problems they have in collecting and using data.

2023 CMT Awareness Campaign

Sandrine Frederick from Aggelos, after a summary of what has been done in recent years, presents the proposal for the 2023 CMT Awareness Campaign to the assembly.
It will be, as usual, a digital campaign implemented on social networks. It will last 5-6 weeks, focusing mainly on October. We will use the material (videos, social media posts, etc.) from previous years and extend it to all the European Countries members of the Federation. Like last year, communication will be focused on diagnostic wondering and raising awareness of CMT.
The targets will be specialists, general practitioners, and patients. An editorial strategy will be implemented for the choice of content and message forms (different depending on the social network and the target). Subtitles and translations will be arranged for each selected content.
The impact analysis will follow the publications.
Attached is the presentation.

Trials on CMT

Filippo Genovese provides a quick summary of what's going on in clinical trials on CMT. The presentation is attached to these minutes.

Various

Ingolf Pernice was elected a member of the Board of Directors of EFNA. Our warmest congratulations to Ingolf for this position; we trust his presence to encourage EFNA to deal more with neuromuscular diseases in general and with CMT in particular.

The General Meeting is declared closed at 6,30 pm. We thank all those present. See you next year.

Date 10/06/2023

Daniel Tanesse
President

Marco van der Linden
General Secretary