2022 General Meeting Report

Berlin, 18/06/2022

Participants in presence

Daniel Tanesse – President of the Federation – delegate CMT France
Filippo Genovese – Vice President of the Federation – delegate ACMT-Rete
Ingolf Pernice – Vice President of the Federation – delegate DGM – CMT group
Arabela Acalinei – member of the Federation board – delegate Neuro Move CMT
Simon Bull – member of the Federation board -delegate CMT UK
Maria Trentadue – delegate AICMT
Donata Albergo – AICMT
Silvia Kendler – delegate CMT Austria
Andreea Szabo – delegate CMT Romania
Delia Hotea – Delia Hotea – Vice President on Neuro Move CMT
Inbal Ben-David – President of CMT Israel
Nechemya Nate Rubin – founder of CMT Israel
Marina Brocca – secretary of the Federation
Margaux Cillan – Aggelos (she attended the meeting from 4.00 pm)
Sandrine Frederick - Aggelos (she attended the meeting from 4.00 pm)

Participants by Zoom

Dany Maes – Treasurer of the Federation – delegate from Spierziekten Vlaanderen
Marco van der Linden – General Secretary of the Federation – delegate from Spierziekten Nederland
Luisa Porzio Perrero – delegate from Progetto Mitofusina2
Ana Navarro – delegate and secretary from Federación ASEM
Zoltán Grosz –WonderFlora & CMT (Hungary)
Rita Drávucz - delegate from WonderFlora & CMT (Hungary) she has been connected for a few
Radim Mazanec – representative of the Czech Republic CMT association

Welcome to the Participants

The President and the Vice President welcome and introduce everyone, the delegates connected by Zoom and those in the face-to-face meeting.
The Federation currently includes 11 Full Members, 5 Associate Members, and 3 Partners (CMT-NET, EAMDA & Ganglion Skopje).
New positions:
Barbara CHALOUPECK has been elected President of CMT-AUSTRIA; Silvia Kendler is the delegate from the Austrian association.

Arabela ACALINEI, our delegate of NEURO-MOVE ROMANIA, has been elected President of the EAMDA.
Congratulations to all of them!

Quorum

All the Full Members are attending the meeting. The General Secretary confirms that the quorum has been reached.
Approval of the 2021 General Meeting report: the report is approved.

2021 Moral Report – Federation's activities

1. European CMT Awareness Campaign

Thanks to a grant of 75.000 € from Pharnext, our main realization in 2020 was again our European CMT Awareness Campaign, the fifth one.
The project was presented by zoom to us by Aggelos during our 2021 General Meeting.
It took place in October in 7 European countries: Belgium, France, Germany, Italy, Netherlands, Spain, and the UK, with an extension in some other countries – Israël & Romania –thanks to the help of our Member associations.
The targets were general practitioners, specialists, health professionals, and the general public.
The digital campaign aimed at doctors ran very well in almost all the countries
The Google AdWords campaign, thanks to Google Grants, mainly aimed at the public, has been successful.
In general, the traffic on our websites increased; the number of likes and followers on FB, Instagram, and Twitter also augmented.
The details of the 2021 CMT Awareness Campaign results were presented on November 29 by Irina DOBRE - Aggelos - and are at your disposal.

2. Rare Disease Day – Faces of CMT

We participated in the international competition called "Faces of CMT.
Worldwide, CMT patients were asked to send a photo showing the challenges of living with the disease and the strategies to overcome it. All associations were invited to spread the competition's news among their members to let them send their photos. The initiative ran alongside Rare Disease Day (RDD), and the winners were announced on February 28 to celebrate this important date consecrated to rare diseases. Participants had until February 21 to submit their photo (one photo per entrant) with a short description (less than 100 words). Judges from CMT USA, HNF, and ECMTF selected the 1st, 2nd, and 3rd prize entries. There were two categories: over and under 16 years old, and three winners were chosen in each category and prized with EUR 50 vouchers paid by CMT USA, HNF, and ECMTF, with EUR 75 contribution from Pharnex.
The winners of the "over 16" category were: Sandra Fernandez Vega (Spain), Michela Padovan (Italy), and Laura Llorens (France).

The winners of the "under 16" cathegory were: Brook Phipps (USA), Seamus O'Neill (USA), and Ashlyn Montisanti (USA).

3. **Participation** in several **meetings**, most of them unfortunately online:
   - Annual Meeting of the SFNP (French Speaking Society of the Peripheral Nerve) in January
   - Meeting EFNA by Zoom in January
   - Meeting RARE 2030 by EURORDIS in February
   - EFNA General Assembly by Zoom in April
   - Meeting ERN-Euro NMD by Zoom in June
   - HealthTech For Patients, in June
   - Webinaire EFNA, in June
   - PNS Meeting by zoom, in June
   - EFNA Meeting “Personalised Healthcare”, in November
   - Virtual Patient Family Conference of CMTA, in November
   - Several meetings with Aggelos for the organization of the Awareness Campaign.

NB: Participating in scientific meetings is not only a chance to learn more about our illness, but it’s also an opportunity to lobby with the labs & companies that sponsor these events, and with the scientists. Our willing is to make our Federation better known, store valuable contacts, and consolidate our ties with other associations.

4. **ECMTF’s Board Meetings**

The Board meets every two months (via Zoom). The Meeting Report is regularly sent to all Members.

Conclusions on the Federation’s 2021 activity

The Federation is now made up of nineteen members, and we have continued to strengthen it and its visibility and credibility.
We have maintained close contact with CMTA, HNF & the CMT Research Foundation, the three associations representing American 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 the patients themselves.
In Europe alone, we are considered to be 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), EFNA (the European Federation of Neurological Associations), and TREAT-NMD.
Last but not least, labs working on drugs for CMT are asking us for their studies and therapeutic trials: Augustine Therapeutics (Belgium);

Applied Therapeutics (USA);
Nervosave Therapeutics (France);
Orizon Genomics (Spain);
InFlectisBioscience (France);
Pharnext (France).

The General Secretary notes that there are no abstentions or against for the approval of the President's Moral Report; the Moral Report is unanimously approved.

Financial Report

The Treasurer presents the financial and accounting balance sheets for 2021.
The pandemic of the last two years has helped lower our expenses (no travel and no face-to-face meetings) so that the 2021 financial balance is mainly positive.
The balance sheet shows a positive cash flow.
The General Secretary notes that there are no abstentions or against for the approval of the Treasurer's Financial Report; the Financial Report is unanimously approved.

Election of the second Vice President

The President wishes to strengthen the Board and its possible replacement in case of need.
The candidate for the position of second vice president is Ingolf Pernice.
The General Secretary notes no against and abstentions to Ingolf Pernice's second Vice President election; the election is unanimously approved. Congratulations!

Election of new Board Members

The Federation received no applications by Full Member delegates to become part of the Board.
The Board remains made up of the following members: Daniel Tanesse (President); Filippo Genovese (Vice-President); Ingolf Pernice (Vice-President); Dany Maes (Treasurer); Marco van der Linden (General secretary); Arabela Acalinei (Director); Simon Bull (Director).

Before continuing, we asked for a few words from the Delegates connected by Zoom.
Luisa Porzio Perrero tells us about a new project: her daughter created the first Italian integrated dance company, where professional and wheelchair dancers dance together, giving a beautiful example of integration. The Progetto Mitofusina2 association also supports many sport-related projects as these are excellent integration vehicles and, of course, research on CMT2A. They hope they will soon give us good news for therapies.
Ana Navarro is the secretary of Federación ASEM, a Spanish organization grouping Twentynine associations with multiple pathologies. They agree with us on the need to create a CMT association in Spain, but, on the other hand, they cannot be the promoters since they deal with several different diseases. They assure, together with the ECMTF, their support to those who wish to create such an association, and they would be happy to be able to embrace them in the Federación ASEM.
The European CMT Federation will be available to help birth a CMT association in Spain.

Zoltán Grosz and Rita Drávucz introduce the WonderFlora & CMT foundation. The organization's primary goals are to inform Hungarians about CMT and help patients and their parents find solutions for this condition. They joined the Federation intending to make fruitful collaborations. Even if they are a new and young organization, they have many plans: they translated information and documents on CMT for their members and contacted Hungarians and international specialists.
The Federation is happy to be able to help this young and dynamic foundation as much as possible, and we will share the Federation and the other associations' information with them.
Radim Mazanec - the Czech Republic CMT association is the oldest in Continental Europe; founded in 1999, with 250 members, they publish news on CMT every three months.

Actions and Projects 2022

1. **2022 Forecast Financial Report**

The Treasurer presents the 2022 financial and accounting balance sheets.
The costs will be higher since trips are planned (and made) to participate in international congresses and for the General Meeting. Despite this, it is expected to have a positive balance in 2022 financial management.
Likewise, a positive balance for the treasury is expected at the end of 2022.

2. **6th CMT Awareness Campaign**

Sandrine Frederick and Margaux Cillan from Aggelos communication company presented the visuals and strategies for the 2022 Awareness Campaign.
The key points are:

- Enhancing and capitalizing on existing video content
- To ensure consistency in the campaign
- Supporting an 'engagement' campaign
- A single message to repeat
- Setting a specific graphic environment
- Being by the side of the specialists
- By focusing on the patients

A discussion follows Aggelos' presentation, especially on the fact that falling is not a significant symptom in CMT and on the social media use for the Campaign.
The presentation is available to all participants. Everyone can send their opinion and suggestions that will be considered by Aggelos and integrated into the final guidelines of the Campaign.

3. **First European CMT Specialists' Conference**

On 9 and 10 June 2023, will take place in Paris the First European CMT Specialists' conference.

We chose this town because it is here that the CMT was discovered.
We will bring together researchers, clinicians, doctors, physiotherapists, and professionals who must work together to find a cure or combat the symptoms of CMT. There will also be representatives of the press.
Daniel and Ingolf drew up the guest list of speakers. Everyone responded positively and enthusiastically to the invitation.
Among the guests we mention, by way of example, Mary Reilly, Stephan Zuchner (Charcot-Marie-Tooth and Related Neuropathies Consortium (CMTR) Representative), and the President of CMTA.

Ingolf illustrates the main reasons that prompted us to organize such an event.
Some researchers feel there is insufficient cooperation for CMT, a rare disease; furthermore, the ordinary scientist doesn't meet CMTs in his professional life; there is a lack of communication of information and experience. We must fill this gap, bringing together researchers, clinicians, patients, and therapists.
We not only want to connect patients and specialists but also specialists with each other. Specialists are divided into groups that do not communicate with each other. If biological researchers, biochemists, geneticists, clinicians, and therapists combine experience and scientific interest in research, we believe that useful synergies can be created to discover therapies.
The Conference program is divided into two: the first part is dedicated to updating research; the second part to strategic seminars with the threefold objective of creating an association of specialists, making a patient database and mobilizing patients (who can actively contribute to research with donations).
At the moment we are looking for funds for the conference, we foresee a budget of 70 - 80 thousand euros.
We lack specialists and associations from Eastern Europe; I invite everyone to refer specialists and delegates from these countries ".
A page will be created on our site specially dedicated to the Conference.

4. Participation in meetings concerning the CMT and, or the ECMTF

SFNP Annual Meeting in Paris, January
Webinar PNS/CMTR, February
PACARARE (rare diseases) in Nice, March
Workshop EJPRD (on Biological Markers) in Nice, March
10th Meeting on Peripheral Neuropathies in Paris, March
Star Advisory Board of CMTA, in Miami, May
PNS Annual Meeting, in Miami, May

5. Rare Disease Day - “CMT Art Competition”

This initiative mirrors the 2021 competition organized to pay tribute to the month dedicated to rare diseases. Last year the contestants were invited to submit a photo; this year, they are invited to send a drawing (or a work of art).

6. Pursuit of the principal Statute's objectives

To help the labs with their European projects for CMT (studies and trials).
To help existing associations – members of the Federation – become better known and more powerful.
To promote the creation of CMT PAGs where there are not (in Europe).
To find the budget to extend our Awareness Campaigns to Eastern European.

Extension and Consolidation of the Federation

1. New Members

We have a new member: WonderFlora & CMT from Hungary.
We hope soon the Czech Republic and Portugal associations will join us.
We have contact with a group of patients in Poland, but this country still has no association.

2. Search for Sponsors

Many contacts are made with laboratories to obtain funding, if not immediately, at least for the near future. The President and the secretary had meetings with:

- TAYSHA, a laboratory interested in the CMT diseases
- Applied Therapeutics, a laboratory working on the SORD Project (CMT2)
- CMT4B3 Research Foundation (zoom meeting and a F2F)
- Pharnext laboratory, currently the sponsor of our awareness campaigns and outsourcing.

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

Other Matters

1. Federation's Organization

Internal organization
The Federation has no employees and no office, and we are all volunteers already overloaded with work and tasks in our national associations. Therefore, the Federation needs to outsource the execution and administration of the main activities.
This work is entrusted to LexicaMente (the secretary's company), and it is paid with the grant from Pharnext. The secretary invoices the Federation and provides monthly activities reports.
In 2021 they covered a wide range of tasks: publications on the Federation's social media and Website, organization of meetings, accounting, administration tasks, secretarial work, "welcome desk" by mail, search for sponsors, etc.
We do not forget Irina DOBRE, from Aggelos agency, who brought us her help and skills to improve our site and create communication materials. She left AGGELOS at the end of 2021 but was replaced by her former assistant – Margaux Cillian – who is with us today.

For the Conference's organization, the Federation hired the agency specialized in health communication Comm-Santé.

External organization

The Federation is a member of the European organizations EURORDIS, EFNA, TREAT-NMD and cooperates with EAMDA and CMT-NET.

2. CMT Trials update

Filippo Genovese presents an update on the state of the art of CMT experiments. The presentation is available for all members.

3. Arabela Acalinei's participation in the EFNA General Meeting

Arabela participated in the EFNA GM (on May 10th,2022) on behalf of the Federation and as President of EAMDA.

She reports that (as we unfortunately know) EFNA focuses a lot on brain health. She approached this topic with EFNA to try to balance the situation. Bringing other neuromuscular diseases (in particular, CMT) to the attention of EFNA strategies is the plan for the future, and we will be part of this process.

Also, Arabela and the Austrian and Hungarian CMT associations are planning to mobilize the Eastern part of Europe, where there is a more significant lack of expertise in CMT.

Date, 04/07/2022

President Signature
Daniel Tanesse

General Secretary Signature
Marco van der Linden