# ECMTF 2026 General Assembly Report

**01/05/2026. 3 PM CEST, Vienna**

The following Delegates of the Federation's Member Associations were present:

In person
**Filippo Genovese** – Delegate from ACMT-Rete (Italy), Full Member, President of the Federation
**Ingolf Pernice** – Delegate from the CMT Group in DGM (Germany), Full Member, Vice President of the Federation
**Marco van der Linden** – Delegate from CMT group in Spierziekten Nederland, Full Member, Secretary of the Federation
**Simon Bull** – Delegate from CMT UK, Full Member, Treasurer of the Federation
**Alexander Leysen** - Delegate from Spierziekten Vlaanderen (Belgium), Full Member
**Alexandre Hoyau** – Delegate from CMT France, Full Member
**Arabela Acalinei** – Delegate from Neuro Move CMT (Romania), Full Member, Partnerships & funding director
**Rita Drávucz** – Delegate from WonderFlora & CMT (Hungary), Full Member
**María Fernanda Lemos Ojea** - Delegate from CMT Spain, Full Member
**Tamara Navarro Vicente** - CMT Spain member
**Barbara Chaloupek** – Delegate from CMT Austria, Full Member
**Klaus Mannsberger** – CMT Austria member
**Silvia Kendler** – CMT Austria member
**Andreea Maria Szabo** – Delegate from Asociația Charcot Marie Tooth România (Romania), Full Member
**Ladislav Krasa** - Delegate from Společnost C-M-T, Associate Member
**Tina Frisch** - Delegate from Muskelsvindfonden (Denmark), Full Member

Online:
**Michela Padovan** - Delegate from AICMT (Italy), Full Member
**Katherine Forsey** – Delegate from CMTA (USA), Associate Member
**Helle Permin Talbot** - Muskelsvindfonden (Denmark) member

**İpek Badırgalı**, SETA Consulting – communications partner (not a member)

**Welcome to the participants**

The President opened the 2026 General Assembly by welcoming both the delegates who had travelled to Vienna and those connected remotely. The meeting was framed not as a routine statutory obligation, but as a deliberately hybrid governance moment designed to combine formal decision-making with a more ambitious educational and strategic component.

## Quorum

The Secretary confirmed that a majority of full members were present and that no proxies had been submitted. Quorum was, therefore, reached and the Assembly was duly constituted for its formal business

## Approval of the minutes of the 2025 General Meeting

The minutes of the 2025 General Meeting, which had been circulated in advance, were introduced by the Secretary. No further questions were raised from the floor. The minutes were therefore confirmed as approved.

## Member organisation roundtable and flagship-project exchange

All members present gave a short presentation on a recent highlight of the work and a future highlight. These presentations have been collected and can be downloaded by following the link at the bottom of the report.

## 2025 Activity Report (Presented by Filippo Genovese)

The President's activity report for 2025 presented that year as one of scientific institutionalization. The underlying message was that ECMTF had crossed an important threshold: it was no longer only convening goodwill and ambition, but had begun to convert those assets into governance, financing, scientific continuity, and operational follow-through.

### Governance and administrative consolidation

The first set of points concerned the federation's internal consolidation. The prolonged banking and statutory difficulties that had complicated ECMTF life for a considerable period were finally moving toward resolution. The President explained that the statutes had been updated and that the difficult Belgian administrative process had at last produced an operational result: the federation had regained functional access to its banking, allowing the Treasurer and President to manage accounts properly. This was not presented as mere bureaucracy. It was framed, correctly, as a governance milestone because it makes transparent handling of grants, sponsor income, reimbursements, and budgeting possible on a professional basis. The same section also acknowledged the role of Alexander Leysen and the Belgian support around the statutory update.

### Membership expansion and positioning in the wider rare-disease ecosystem

The report highlighted growing international reach through the Chinese associate member Qianlixing CMT Support Home, described as connecting more than 1,600 families and almost 4,000 patients. This was not framed as symbolic expansion for its own sake, but as a real widening of the advocacy ecosystem and of potential exchange in patient support, awareness, and research visibility. At the European level, ECMTF's continued participation in broader rare-disease structures — especially through EURORDIS and the Council of European Rare Disease Federations — was presented as strategically important. The argument was that CMT priorities advance faster when they are articulated inside the larger rare-disease movement rather than in isolation.

Survey-based evidence building

A notable part of the 2025 report concerned evidence building through wider surveys. The President stressed the importance of the EURORDIS Rare Barometer survey on resources for daily living with rare conditions and openly noted that, although CMT participation existed, the response volume could and should have been higher. This mattered because such surveys translate everyday difficulties into cross-condition evidence that is legible to policymakers. A second survey highlighted during the GA was the EFNA "Invisible Burden" work, whose results underscored stigma, disbelief in medical encounters, and the importance of symptoms such as fatigue, pain and sleep problems. By bringing these findings into the GA, ECMTF signaled that it wants to anchor future care-access work in more than anecdote.

The 2nd European CMT Specialists Conference in Antwerp

The Antwerp conference was presented as the flagship achievement of 2025. The meeting brought together 136 delegates from four continents and had visibly consolidated Europe as a credible convener of CMT science, patient partnership, and cross-sector dialogue. The President briefly but meaningfully revisited the conference structure: the "patients as partners" paradigm, the opening by Prof. Vincent Timmerman, the message from the EU Commissioner, the scientific plenaries on basic science, diagnostics, therapeutic approaches, clinical-trial methodology, and access to therapy, and the fishbowl workshops that generated practical project follow-up rather than merely polite discussion.

What mattered most in the GA context was not a full re-run of Antwerp content, but its institutional consequences. The Daniel Tanesse Prize honored six young researchers. The conference evaluation was extremely strong, with an overall rating of 9.11/10 and especially high marks for scientific quality and networking. Most importantly, Antwerp produced tangible outputs that could continue to work after the event — reports, interviews, collaborations, and the formal launch of ECRA. The president stressed the importance of sharing the conference deliverables with the members' patients' and scientific community worldwide.

Launch of ECRA and the longer scientific legacy

The report described the official launch of the European CMT Research Association (ECRA) as one of the most durable outcomes of the Antwerp process. ECRA was presented as a structured space bringing researchers, clinicians, patients, and industry together so that European CMT research is less dependent on isolated projects and more capable of continuity. In the GA discussion, ECRA was repeatedly linked not only to scientific prestige but to practical follow-through: dissemination of conference deliverables, collaborative workstreams, and the possibility of maintaining a truly European research conversation in a fragmented post-Brexit environment. ECMTF is represented within the ECRA board by Alexandre and Filippo.

Communications, webinars, and congress representation

The 2025 report also covered the 9th awareness campaign, the webinar cycle, and congress participation. The communications results presented by SETA showed strong growth in profile visits and content output. At the same time, the discussion did not hide the operational weaknesses: there had been too few real community visuals, too few member-submitted videos, and too much friction around translation timing and formatting. This candor was useful because it prepared the ground for the 2026 redesign. The webinar

series was described as an important access tool for those unable to travel, and the 2025 presence at the PNS meeting in Edinburgh was presented as strategically productive, especially for networking with companies and advancing patient representation inside the peripheral-nerve field.

The Secretary requested approval of the 2025 Activity Report, which was approved unanimously.

**2025 Financial Report (Presented by Simon Bull)**

Simon Bull described 2025 as a demanding year for the treasurer because banking disruption had forced more manual and improvised handling than would normally be acceptable. Even so, the final numbers showed an organisation that had become materially more capable, above all because Antwerp-related grant income could now be tracked and managed properly.

- **Income:** Primarily from (conference) grants, membership fees, and sponsorship.
- **Expenditures:** The 2025 awareness campaign, costs associated with the previous General Assembly and Antwerp congress.
- **Closing Balance:** The year ended with a positive balance of €91.807,--

The Secretary requested approval of the 2025 Financial Report, which was approved unanimously.

**Discharge of the Directors**

The Secretary asked whether anyone opposed or abstained from discharging the Board for the policy and strategy of the past year. No opposition or abstention was recorded, and the discharge of the directors was therefore adopted unanimously.

**Actions and Projects 2026/2027**

The second major part of the General Assembly focused on 2026 and beyond. The President presented the strategic shift as one from drafting to execution across six pillars: governance, policy, scientific valorisation, strategic projects, congress activation, and awareness and youth. The spirit of this section was important. The federation is no longer only explaining why CMT deserves attention; it is beginning to specify how a European CMT ecosystem should function, what evidence it needs, where the inequalities are, and how patient organisations should act inside that architecture.

<u>Governance, policy, and network consolidation</u>

The Vienna meeting itself was described as part of the strategy. It was presented as the model for a repeatable annual hybrid GA that combines formal governance with educational content and more meaningful in-person trust-building. The participation of Muskelsvindfonden from Denmark was welcomed as an important broadening of Nordic representation and a sign that ECMTF remains attractive as a platform for collective action. At the policy level, Filippo Genovese reported his participation in the task force shaping the European Blueprint for Rare Diseases, positioning ECMTF not only as a respondent to policy but as an

actor trying to influence future European health-system design upstream. The Board also signaled interest in exploring a move to a more ethically aligned bank now that core operational constraints are easing.

Care Access project and policy-facing evidence

Arabela Acalinei presented the emerging "Care Access" project as a long-term effort to document the inequalities CMT patients face across Europe in rehabilitation, orthotics, reimbursement, waiting times, and access to multidisciplinary care. This discussion was one of the strongest examples of the federation's shift in maturity. Instead of simply stating that care is unfair or fragmented, the project aims to build structured comparative evidence showing where systems fail and what that failure costs patients. The longer-term intention is to convert those findings into a strong European position paper that can be used with EU institutions, national ministries, ERNs and other clinical networks.

CMT Patient Journey with EURO-NMD

The patient journey was one of the core strategic projects discussed on both days. The President described it as an instrument meant to capture what the "common CMT patient" and the wider range of real CMT patients go through from first symptoms to long-term follow-up, while integrating both clinical pathway and human experience. Arabela stressed that the document must go beyond symptom chronology: it should include emotional burden, psychological support, employment, family planning, social navigation, and the fact that patients are too often left to coordinate multidisciplinary needs alone.

A central challenge identified in Vienna was diversity. Members insisted that the final journey must not accidentally reflect only mildly affected or well-served profiles. It must include wheelchair users, ambulant adults, children, parents, different national reimbursement realities, and the absence of multidisciplinary teams that many adults still face. The target remained to deliver a draft to EURO-NMD by July 2026, with member input collected quickly and methodically in the meantime.

Nutrition, national standard-of-care material and practical resource exchange

The GA also touched on an apparently smaller but actually very practical item: the EURO-NMD nutritional-care flyer. Members were invited to help translate and disseminate it. The discussion quickly widened into a more important exchange about national standards of care. France indicated that it already has a more developed national standard-of-care document for CMT and offered to share it. This mattered because it opened the possibility that the federation can circulate not only campaign content but also clinically useful documents that members may adapt in their own countries.

Cross-border burden mapping and awareness initiatives

The President explicitly encouraged members to think in cross-border project terms and to inform the federation when they do so, so that ECMTF can amplify visibility and coherence. Two examples were highlighted. First, work is being prepared toward an ENMC workshop proposal on the economic burden of CMT across Europe. The logic is strategic: if the health-economic burden can be quantified properly, ministries and systems can be pressed not only morally but economically. Second, a cross-border awareness initiative in France involving a very long-distance walk was highlighted, with the specific request that the French association connect the initiative to local patients along the route where possible.

Webinar series, digital tools, and advocate support

The Board announced the intention to run a 2026 webinar series focused more explicitly on patient organizations and patient advocates. Planned themes included free or low-cost tools for running associations, nutrition, patient education, and clinical-trial literacy. This was also linked to a pragmatic procedural decision: because of time pressure in Vienna, the planned session on online tools and AI support for patient advocates would not be developed fully in the seminar room but would instead become material for the first webinar in the new series.

ERDERA, Novartis and research-facing integration

ECMTF reported involvement in two ERDERA-related research applications, with one proposal advancing to the second stage. The specific names and work-package structures were part of the slide material, but the most important point for the GA was the principle: ECMTF is increasingly entering research consortia not as a decorative patient body but as a real work-package contributor for communication, engagement and public/patient involvement. The President also reported a growing collaboration with Novartis following the company's acquisition of DTx Pharma and its work on a PMP22-targeting platform for CMT1A. The significance of this relationship was presented as both symbolic and practical: it is the first time a pharmaceutical actor of that scale is facing CMT in this way, and patient input must therefore be organized intelligently from the start.

ECRA, Antwerp deliverables, and congress activation

The President strongly emphasized that the Antwerp deliverables should now be "valorized" rather than simply archived. The fourteen outputs from the conference, together with the ECRA website and follow-up materials, were presented as resources members should actively use to create targeted content for local websites, social-media channels and professional audiences. Looking ahead, the Board described concrete congress plans for PNS Maastricht and EAN Geneva, including a patient panel / coffee-chat format intended to let patients tell clinicians and researchers what they wish had been understood earlier. Preliminary thinking for the 2027 specialists conference in Cyprus was also noted as an early continuity measure rather than a last-minute planning exercise.

The 10th awareness campaign: communication redesign, realism, and member responsibility

A major 2026 workstream presented in Vienna was the redesign of the awareness campaign. İpek Badırgalı from SETA reviewed the previous campaign honestly: reach and engagement had improved, but the campaign had also suffered from too few authentic visuals, too few patient videos, and avoidable translation delays caused by process and formatting issues. The 2026 concept, therefore, moved to a two-phase structure: an initial phase focused on clinical readiness and innovation for professionals and researchers, followed by a phase focused on patient stories, outreach, and advocacy for the general public and policymakers. The communications channels would also be more explicitly differentiated, with LinkedIn and YouTube prioritized for professional-facing content, and Instagram and Facebook for public visibility.

Operationally, the most important change for members was this: national organizations would no longer be expected to produce all translations themselves. Central translation and graphic implementation would be prepared, and members would instead be asked to proofread and validate accuracy, terminology and local nuance. This was meant to reduce volunteer fatigue and improve synchronization. At the same time, the

member burden did not disappear; it changed. The campaign now depends heavily on members providing real photographs, short patient videos, testimonials, local intelligence on suitable influencers, and sensible feedback on posting frequency for their national communications ecosystem.

**Projected Budget (Presented by Simon Bull)**

The Treasurer presented the 2026 budget forecast; the figures should be read as a working financial plan rather than a finalized membership snapshot.

**Clinical Trials Update (Presented by Katherine Forsey, CMTA)**

Katherine Forsey again provided a very clear and comprehensive update in the CMT clinical trials field. Her talk made clear that the CMT pipeline is diversifying at unprecedented speed, but also that the field is now entering a more difficult phase in which endpoint choice, regulatory logic, communication to patients, and company decisions can shape outcomes as much as scientific promise itself. Her presentation can be downloaded by following the link at the bottom of this report.

The meeting ended with a practical conclusion rather than a rhetorical one. Participants were asked to stay in touch especially on the CMT Patient Journey. The meeting was declared closed at 6.00 PM; the ECMTF board members thanked everyone who attended.

All presentations and documents from the meeting are available here: https://tinyurl.com/ECMTFGA2026

Bruxelles, 23/5/2026

***Filippo Genovese***
President

***Marco van der Linden***
Secretary