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This Networking event has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 82557

1st European Charcot-Marie-Tooth Specialists Conference

"TOGETHER AGAINST CMT"

Program

with the support of:



PARIS 9 & 10 June 2023



Organized by the
European Charcot-Marie-Tooth Federation



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EDITORIAL:

"Together against CMT" is the watchword of our initiative to bring together European scientists, clinical researchers, and therapists specialized in CMT, to join their efforts in developing effective causal therapies for CMT.

The **European CMT Federation** uniting most of the CMT advocacy groups across Europe feels particularly called to stimulate and promote interdisciplinary cooperative research in the interest of all patients affected.

We simultaneously strive to **mobilize the patients** to cooperate more closely with the specialists involved and to contribute as they can (in studies and with their data) to broaden the basis for successful research.

The different groups of specialists no doubt each already have their own gatherings and schemes of cooperation, but for the first time we call on you to create synergies and innovative ideas **in a joint conference**.

And we are happy to include representatives of the profession and of organizations from overseas so as to learn from their experience and stimulate cooperation **also on the global level**.

FRIDAY 9TH JUNE:

13.00 Registration – refreshments / Exhibitions

14.00 Opening Plenary:

- Welcome: Daniel TANESSE, President of CMT-EUROPE (ECMTF)
Ingolf PERNICE, Vice-President of CMT-EUROPE, Conference Manager
- Video message: Stella KYRIAKIDES, EU Commissioner for Health and Food Safety
- Greetings: Alexandre MÉJAT, Director of EURORDIS (Europe)
- Introductions: « CMT as a common challenge for scientists, clinicians and therapists – disciplinary cooperation and potential of interdisciplinary synergies »
- **European** projects & perspectives: Shahram ATTARIAN
- **American** projects & perspectives: Stefan ZÜCHNER

15.00-16.30 Working groups – Three disciplinary approaches to problem solving

Bio and medical sciences: From data (management and analysis) to therapies.

- Co-moderation: Michael SEREDA
Filippo GENOVESE
- Rapporteur: Rafael SIVERA
- Presenters: Davide PAREYSON
Francisc PALAU MARTINEZ
Wolfgang M. PERNICE
Helena F. PERNICE

Clinical diagnosis and treatment: Potential of genetic analysis and engineering.

- Co-moderation: Peter DE JONGHE
Arabela ACALINEI
- Rapporteur: Maïke DOHRN
- Presenters: Valérie DELAGUE
Angelo SCHENONE
Jan SENDEREK

Therapeutic practice and feedback: Challenges and specific tasks for the therapists.

- Co-moderation: Carsten SCHRÖTER
Alexandre HOYAU
- Rapporteur: Roberto CANNATARO
- Presenters: Fabian CALE
Gita RAMDHARRY
Mel MANDARAKAS

FRIDAY 9TH JUNE:

16.30 Coffee break / Exhibitions

17.00 Plenary II:

- Chair: Mary REILLY
- Comments: Pavel SEEMAN
- Rapporteurs of working groups: Rafael SIVERA, Maïke DOHRN & Roberto CANNATARO
- Podium: Highlights from the working groups
- General discussion: key insights and learnings and then open questions

18.00 End of first day discussions – departure for the Maison de l'Amérique Latine

20.00 Aperitif & Gala Dinner:

MAISON DE L'AMÉRIQUE LATINE – 217, boulevard Saint-Germain – 75007 Paris

SATURDAY 10TH JUNE:

9.00-10.30 Working groups – Strategies: Creating synergies of the three approaches

Cooperation:

Establishing a "European CMT Research Association (ECRA)".

- Co-moderation: Laurent MAGY
Simon BULL
- Rapporteur: Sabrina SACCONI
- Presenters: Tim VANGANSEWINKEL
Teresa SEVILLA MANTECÓN
Lisa REINECKE

Data management for CMT: Towards an Integrated European CMT Patient Registry.

- Co-moderation: Alessandra BOLINO
Marco VAN DER LINDEN
- Rapporteur: Andrea CORTESE
- Presenters: Jean-Christophe ANTOINE
Simone THIELE
Thereshina EVANGELISTA

Mobilizing the patients: Scientists, Clinicians and Therapists expectations and advice.

- Co-moderation: Tanya STOJKOVIC
Inbal BEN DAVID
- Rapporteur: Signe VAETH
- Presenters: Oana-Aurelia VLADACENCO
Kleopas A. KLEOPA
Nicolas TRICAUD

10.30 Coffee break / Exhibitions

11.00 Plenary III:

- President: Peter YOUNG
- Rapporteurs of working groups: Sabrina SACCONI, Andrea CORTESE & Signe VAETH
- Podium: key elements from the working groups
- Comments: an American perspective: Katherine FORSEY, CRO of CMTA
- Final plenary discussion

12.30 **General conclusions & perspectives:**
Vincent TIMMERMAN & Ingolf PERNICE

13.00 **Press Conference & interviews**

Discover the Presentation Abstracts

