

ESSENTIAL TREMOR CONFERENCE

How can technological innovation empower patients' lives?

- Date and hour: 20 March 2024, from 14:30 to 16:30.
 Accreditation to enter the EU Parliament from 1:30 pm (more details to follow)
- Location: Room 3H1 Altiero Spinelli building, European Parliament

EXECUTIVE SUMMARY

The Essential tremor conference seeks to raise awareness about essential tremor, a prevalent brain disorder impacting over 60 million people worldwide. Given the European Commission's prioritisation of health, understanding the specific societal costs of essential tremor on European patients is crucial, especially compared to more recognised brain disorders like Parkinson's, which receives significant attention at the EU level. The summit aims to shed light on the importance of giving essential tremor the attention it deserves by delving into patient experiences and their detrimental effects on their quality of life. Exploring avenues for achieving this heightened awareness, the summit will advocate for an overarching holistic approach to address the unique challenges essential tremor poses at the EU policy level.

- How can we effectively communicate the societal costs of essential tremor among European patients, drawing attention to the disparities in awareness compared to more recognized brain disorders like Parkinson's?
- In what ways can we amplify the voices and experiences of individuals affected by essential tremor, ensuring a patient-centric approach to understanding the disorder's impact on their quality of life?
- What strategies can be employed to advocate for a holistic approach at the EU policy level, taking into account the unique challenges posed by essential tremor and ensuring it receives the necessary attention in health policy discussions?
- How can the European Parliament foster collaboration among stakeholders, including healthcare professionals, patient advocacy groups, and policymakers, to collectively raise awareness about essential tremor and address the gaps in recognition and support?

AGENDA

14:30-14:40 Welcoming remarks by hosting MEPs

- Radka Maxová (Czech Republic; S&D)
- Alex Agius Saliba (Malta; S&D)

14:40-14:50 Keynote speech by Insightec

• Giuseppe Carbone, Vice President Europe, the Middle East and Africa, Insightec

14:50-15:00 Keynote speech by Patient association

 Teresa Petrangolini, Director, Patient Advocacy Lab, ALTEMS/ Cattolica Sacro Cuore University

15:00-15:50 Panel discussion

- Frederic Destrebecq, Executive Director, European Brain Council
- Jesus Rueda Rodriguez, Director General, Strategy and special projects & International affairs, MedTech Europe
- Luca Savarese, President Associazione Tremori
- Maarit Matjussi, Chair of ScanShakers
- Katerina Konečná, Member of the European Parliament, The Left

<u>Moderator</u>: Danielle Brady, Policy Analyst Social Europe & Well-Being Programme European Policy Center

- 15:50-16:10 **Q&A session with the audience**
- 16:10-16:20 **Presentation of the Joint Declaration**
- 16:20-16:30 Concluding remarks by the MEPs
 - Radka Maxová (Czech Republic; S&D)
 - Alex Agius Saliba (Malta; S&D)