

## PREVENTABLE Project PrevenTalk Series. Online Event Overview.

The [PREVENTABLE project](#) launched its PrevenTalk series this month. This series of webinars and roundtable discussions will explore the multidisciplinary approach needed to address Rare Tumour Risk Syndromes (RTRS), and its pivotal role in cancer prevention. The first webinar of the PrevenTalk series, “*Understanding and Addressing the Challenges of Rare Tumour Risk Syndromes in Cancer by Uniting Science, Health Management, and Policy*”, was co-organised by consortium partners, the [European Health Management Association](#) (EHMA) and [Sociedade Portuguesa de Inovação](#) (SPI).

The first webinar brought together key stakeholders along the RTRS care pathway including a geneticist, a hospital manager, and policymakers at the national and European level. The PREVENTABLE project coordinator, Dr. Carla Oliveira from the Portuguese Institute for Research and Innovation in Health (i3S), moderated the event by focusing on the challenges and opportunities for addressing RTRS, and pathways for synergising across disciplines.

The event was opened by geneticist, Dr. Hildegunn Vetti, Principal Investigator for Familial Malignant Melanoma at the Haukeland University Hospital and VID Specialized University in Norway. Dr. Vetti presented different approaches for genetic testing and stressed the importance of engaging with geneticists when developing cancer prevention initiatives and strategies, particularly considering the vital need for a multidisciplinary approach in this field.

One size does not fit all when it comes to RTRS. As a hospital manager, advisor for the executive board of Local Health Unit São José and board member of the Portuguese Association of Hospital Managers, Ms. Rachel Chantre outlines the need to support each patient and their families in understanding the complex RTRS care pathways to promote shared decision-making and respect patients’ individuality. “*Hospital managers truly have an important role in helping, handing out and working on patients and their family's literacy around these kinds of conditions*”, states Ms. Chantre. Maintaining high levels of patient awareness and commitment across the lifespan is vital. Though health managers can help at the hospital or primary care level, they cannot do it alone. Ms. Chantre highlights that healthcare professionals and policymakers need to collaborate to develop community engagement and networks that reach patients in their daily lives.

Next, Ms. Alina Senn, Policy Officer and Team Leader at the Health monitoring and cooperation, Health Networks Unit at the European Commission, shared insights on the work and activities addressing rare diseases at the European Union level, including the European Reference Networks (ERN). [ERN Genturis](#), the reference network for all patients with one of the rare genetic tumour risk syndromes, provides healthcare to patients with RTRS and acts as a platform to connect clinicians to support the exchange of specialised knowledge and resources across the European Union. The Commission aims to improve the accessibility of ERNs for patients in member states through the newly launched project called JARDIN (Joint Action on Integration of ERNs into National Healthcare Systems).

At the national level, Dr Ana Povo, the Portuguese Secretary of State for Health, pointed to the importance of sharing key scientific and clinical findings with policymakers to help shape effective evidence-based cancer prevention strategies. Due to the high cost of developing medicines for rare diseases, effective policies targeting prevention are the answer to the social and economic challenges that RTRS presents.

Overall, the webinar highlighted how healthcare professionals and policymakers can take a multidisciplinary approach to addressing RTRS, and ultimately support cancer prevention efforts. As Dr. Vetti stated, *“If we join forces, we can give the best care to our patients with rare tumour risk syndromes”*.

Stay tuned for the upcoming PrevenTalk 2 on October 3rd, 2024 which will dive into the strengths, weaknesses, opportunities and threats of the care pathways regarding the eight Rare Tumor Risk Syndromes covered in the PREVENTABLE project.

To learn more about the project and future updates, [subscribe to the PREVENTABLE newsletter!](#)