



## Newsletter #1

### 1. Welcome to PREVENTABLE

Dear PREVENTABLE community,

Welcome to the first edition of the PREVENTABLE newsletter, your gateway to the latest updates, breakthroughs, and insights in the world of Rare Tumor Risk Syndromes (RTRS) from the PREVENTABLE Consortium. We are thrilled to embark on this journey with you and to share the remarkable work being done by the PREVENTABLE project, funded by the European Commission under the Horizon Europe funding framework.

The PREVENTABLE consortium consists of EU and non-EU partners, nine healthcare centres recognised as healthcare providers of the European Reference Network on Tumour Risk Syndromes (ERN GENTURIS), and experts in health economics, healthcare management and multidisciplinary innovation. The project aims to assess if specialised care preventing advanced disease in families with Rare Tumour Risk Syndromes (RTRS) is cost-effective. This 3-year project addresses clinical, social, and financial impacts in healthcare, aligning with the Horizon Europe initiative for high-quality care.

Our mission is clear: to demonstrate that preventing advanced disease in families affected by RTRS makes a tangible difference in the lives of patients and their loved ones and is cost-effective. Through collaboration, research, and shared knowledge, we aim to shed light on these often-overlooked syndromes and work towards a healthier, brighter future for all affected individuals. Together, we can transform the landscape of RTRS care and bring hope to those in need. We will do so, by providing healthcare decision-makers with data demonstrating that preventing disease in RTRS patients is less expensive than treating it.

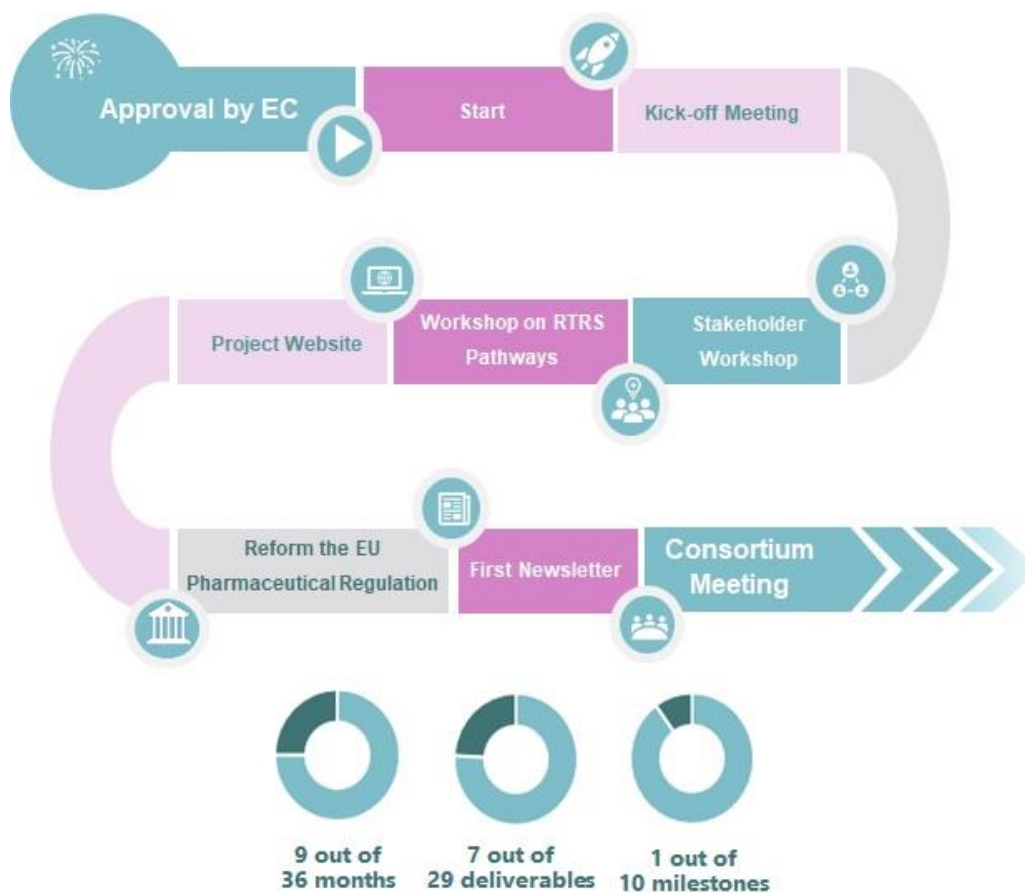
This newsletter will delve into the fascinating journeys, innovative research, discoveries, and advancements that have been made by our amazing partners. In this newsletter, you'll find a wealth of information, from cutting-edge research findings to patient success stories, all aimed at advancing our collective understanding and enhancing patient care. We extend a warm invitation to accompany us on this thrilling expedition into the realm of advanced data exploration and its far-reaching effects on our community. Be on the lookout for intriguing articles, stimulating dialogues, and exclusive interviews featuring the brilliant innovators steering the PREVENTABLE project.

Thank you for being with us and we hope this newsletter will inspire, inform, ignite curiosity and raise awareness about RTRS.

Happy reading!

## 2. Our first months in review

The journey of the PREVENTABLE project has been marked by significant milestones that have propelled us closer to our mission of revolutionizing Rare Tumour Risk Syndromes (RTRS) healthcare. In this first issue of the newsletter, we will take you through some of the major accomplishments that have defined the project's first year, showcasing the dedication, collaboration, and innovation that have made it all possible as figured below.

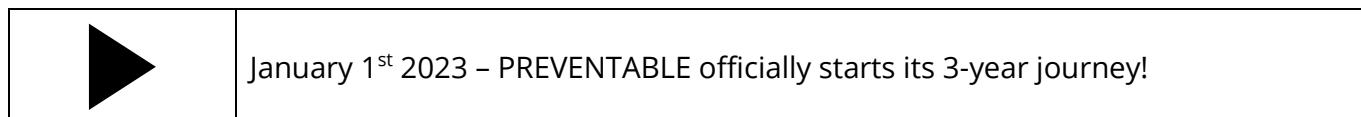


November, 11<sup>th</sup> 2022 – PREVENTABLE is officially approved by the EC under the Horizon Europe Programme with a total budget of 4.6 million euros.

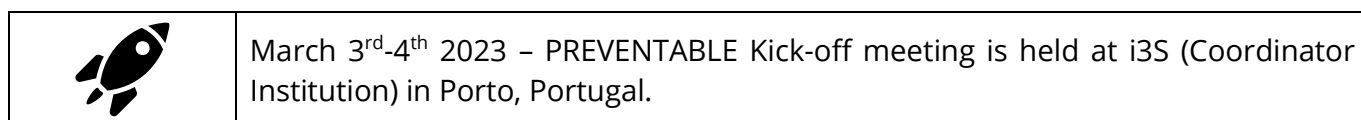
PREVENTABLE officially received approval with project number 101095483 from the HORIZON Research and Innovation Action under the European Health and Digital Executive Agency with a total budget of 4.6 million euros. It embarks on a journey to redefine healthcare for individuals with Rare Tumour Risk Syndromes. The project's focus is on prevention, collaboration with experts, and alignment with EU priorities for those affected by RTRS. With innovation and sustainability at its core,

PREVENTABLE is poised to leave an indelible mark on healthcare, offering a brighter future for individuals living with rare diseases.

Stay tuned for updates on the progress and impact of PREVENTABLE as it works towards transforming healthcare management and improving the lives of those it serves.



The launch of the PREVENTABLE program on January 1st marks the beginning of an exciting journey towards revolutionizing healthcare management for RTRS. With its ambitious goals and collaborative approach supported by incredible partners from 6 EU countries and 2 non-EU countries, PREVENTABLE holds the promise of not only improving the lives of those affected by rare tumour risk syndromes but also serving as a model for comprehensive healthcare management in the future. As the project unfolds, it will undoubtedly bring about transformative changes, benefiting individuals, families, and healthcare systems alike.



The first Consortium Meeting of PREVENTABLE took place at i3S - Instituto de Investigação e Inovação em Saúde da Universidade do Porto, in Porto Portugal, as the Coordinator Institution of the Project

The meeting started with a welcoming session led by the Project Coordinator, Carla

Oliveira, who shared words of appreciation and enthusiasm for the kick-start of such an ambitious project that brings together experts from different disciplines, in a joint effort to positively impact the lives of patients suffering from rare tumour risk syndromes (RTRS) while promoting the efficient use of healthcare resources.

For two days, researchers from fifteen different institutions and eight different countries gathered to share their vision for PREVENTABLE and had the chance to exchange ideas about the activities to be developed in the following months. Moreover, they were gathered in a social program as a way to foster a sense of teamwork and increase the motivation and engagement of the team.

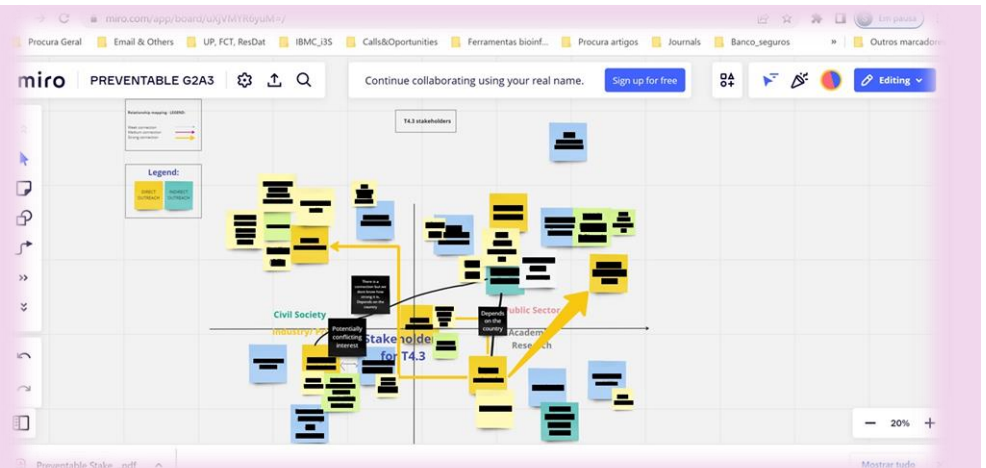


Participants experienced the vibrant social program in Porto, centred around the World of Wine (WOW) in Porto's Wine District. WOW is a cultural and tourist hub featuring seven interactive museums, including the Wine Experience, Planet Cork, Porto Region Across the Ages, The Bridge Collection, The Chocolate Story, Fashion & Fabric, and Pink Palace. Beyond enhancing teamwork, the social program played a pivotal role in boosting motivation and engagement. The positive energy generated during these interactions had a lasting impact on the team's dynamics, contributing to a more cohesive and inspired group poised to tackle the challenges of the PREVENTABLE project collaboratively.



March 30<sup>th</sup>, 2023 – Stakeholder Online Workshop jointly led by SPI and EHMA as an exercise with all PREVENTABLE partners

On March 30<sup>th</sup>, 2023, the consortium conducted a stakeholder online workshop. The workshop serves as a vital platform for engagement and consultation from all consortium members led



by SPI and EHMA. The aim is to identify, categorise, and analyse the relevant stakeholders, laying the foundation for establishing a network and commencing the development of the European Stakeholder Database.

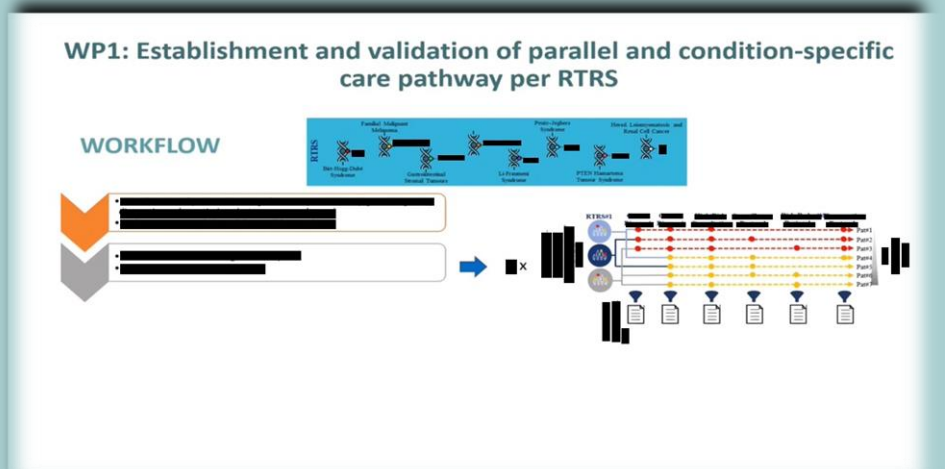
The workshop facilitated understanding and collaboration from various stakeholders and initiated a groundwork for upcoming activities such as “The Preventalks”. The result of this workshop is a stakeholder mapping and their interest in and influence on the PREVENTABLE project from a diverse group of stakeholders which are RTRS patients and their families, research communities, healthcare professionals; associations; and networks, healthcare institutions and management, healthcare industry and services, policymakers and key opinion leaders (KOLs), and the public in general.



April 4<sup>th</sup>, 2023 – Workshop on RTRS pathways of care on Work Package 1

On April 4<sup>th</sup>, 2023, a workshop brought together all WP1 contributing partners to collaboratively work on the preliminary development of care pathways for the 8 RTRS addressed in the project. The primary

objective of the workshop is to identify and categorize the main patient’s profile and clinical presentations, and respective clinical procedures and/or consultations, based on the partners' experience, professional experience and guidelines.



The outcome of this workshop, PREVENTABLE team members from the institutions involved in WP1 define a common strategy for the establishment and validation of parallel condition-specific pathways of care for each of the RTRS addressed in PREVENTABLE.



April 24<sup>th</sup> 2023 – PREVENTABLE Website (<https://preventable.eu/>) is launched.

We are thrilled to introduce you to the PREVENTABLE project's official website, a dynamic online platform designed to be your ultimate resource for Rare Tumour Risk Syndromes (RTRS) knowledge and community engagement.

The PREVENTABLE website is more than just a website; it's a hub of knowledge, a hub of support, and a hub of hope for all those affected by Rare Tumour Risk Syndromes. We invite you to explore, learn, connect, and collaborate with us on this journey to transform RTRS care. Together, we can make a difference in the lives of those who need it most.

Visit us at: <https://preventable.eu/>)

**Preventable**  
SUSTAINABLE CARE FOR RARE TUMOUR RISK SYNDROMES

About ▾ The Consortium ▾ RTRS ▾ Our Research #KnowAboutRTRS News and Events ▾ Contacts 🔍

# Sustainable care for rare tumour risk syndromes

The PREVENTABLE project began in January 2023 and was created to assess the clinical, social and financial impact of applying multidisciplinary and specialized care to prevent advanced disease in families suffering from Rare tumour Risk Syndromes (RTRS). In a complex disease context such as the case of RTRS, consensus clinical guidelines and cumulative experience and knowledge of RTRS-specialized teams is essential for proper management of the diseases.

[Learn More](#)



April, 26<sup>th</sup> 2023 – Reform of the EU pharmaceutical legislation: what's there for rare diseases?

The European Commission released a package of proposals (the “[pharmaceutical package](#)”) to reform the EU pharmaceutical legislation. The package includes a proposal for **a new directive** and **a new regulation** to revise and replace the existing general pharmaceutical legislation ([Regulation 726/2004](#) and [Directive 2001/83/EC](#)), and the legislation on medicines for children and for rare diseases ([Regulation 1901/2006](#) and [Regulation 141/2000/EC](#), respectively). The proposal is completed by **a communication** and **a Council recommendation** to step up the fight against antimicrobial resistance; the Council adopted the [recommendation](#) on 13 June 2023. The reform of the EU pharmaceutical legislation is part of the [Pharmaceutical strategy for Europe](#), one of the pillars of the [European Health Union](#).

**Objectives** of the “pharmaceutical package”:

- Ensure **timely and equitable access** to safe, effective, and affordable medicines for all patients across the EU
- Enhance the **security of supply** and **availability of medicines** to patients, regardless of where they live in the EU
- Create an attractive and innovation-friendly environment for **research, development, and production** of medicines in Europe
- Support **environmentally sustainable medicines**.

**Why is it important for rare diseases?**

This reform will merge the [Orphan Regulation](#) and the [Paediatric Regulation](#) with legislation for all medicinal products with regards to their quality, safety, and efficacy. However, **specific requirements** will still apply for the research and development of medicines for children and patients with rare diseases. The new legislation introduces **incentives for industry** to produce medicinal products for unmet medical needs and rare diseases. According to the new European Commission's proposal, pharmaceutical industries producing medicines for rare diseases will benefit from a longer period of market exclusivity compared to general pharmaceutical products. Additional periods of market exclusivity will be granted for companies that address a “high unmet medical need”, launch the medicine in all the EUMS, or develop new therapeutic indications for an existing



authorised orphan medicine. **Patient associations** [welcomed](#) the proposal, but asked for additional incentives to increase research infrastructures and investment. Additionally, patients representatives called for amendment to the proposal that could make the European market more competitive compared to the US and China and ultimately improve access to rare disease medicines.

### What are the next steps?

The package is now submitted to the European Parliament and Council for approval. Feedback is open to the public see here - [Revision of the EU general pharmaceuticals legislation \(europa.eu\)](#).

### Other EU updates on rare diseases

The future Spanish, Belgian, and Hungarian Presidencies of the Council of the EU have included rare diseases among their health [priorities](#), together with cardiovascular diseases, mental health, and the global health initiative.

### How would PREVENTABLE benefit from this?

Both the reform of the pharma legislation and the Presidencies' priorities show an increasing interest in rare diseases on the EU health agenda. By encouraging industry to develop medicinal products for rare diseases', the package could foster RTRS early diagnosis and monitoring, eventually spotting high-risk carriers prior to disease development and ultimately contributing to a better quality of life for people living with RTRS. The package has the potential to contribute to PREVENTABLE's main aim to maximise RTRS prevention and survival rates.

### Useful resources

- [1] [https://www.europarl.europa.eu/RegData/etudes/BRIE/2023/749789/EPRS\\_BRI\(2023\)749789\\_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2023/749789/EPRS_BRI(2023)749789_EN.pdf)
- [2] <https://www.europarl.europa.eu/legislative-train/theme-promoting-our-european-way-of-life/file-revision-of-the-pharmaceutical-legislation>
- [3] <https://data.consilium.europa.eu/doc/document/ST-10597-2023-INIT/en/pdf>



October 2023 – First PREVENTABLE Newsletter

In October 2023, the PREVENTABLE project introduced a groundbreaking addition to its communication arsenal: the PREVENTABLE Newsletter. Knowledge is the most potent weapon in the quest to transform RTRS care. The PREVENTABLE Newsletter is your gateway to this knowledge and a testament to the power of collaboration and innovation. Stay tuned for the next issue.



October 27<sup>th</sup>-28<sup>th</sup> 2023 – Second Consortium meeting held by IDIBGI and i3S, in Girona, Catalonia, Spain



On October 27th and 28th, 2023, a pivotal event – the Second Consortium Meeting of the PREVENTABLE project, took place in Girona, Catalonia, Spain. This gathering, which was hosted by the renowned Girona Biomedical Research Institute (IDIBGI) and Instituto de Investigação e Inovação em Saúde da Universidade do Porto (i3S) in Girona, Spain, marked another significant step in the mission to revolutionize healthcare for individuals affected by Rare Tumour Risk Syndromes (RTRS).

The Second Consortium Meeting of PREVENTABLE was more than just a gathering of experts; it is a forum for delivering progress, sharing of experiences in handling patients, fostering the collaboration and strengthening the bond through social activities. As the project moves forward, it does so with a clear vision: to enhance the lives of individuals with Rare Tumour Risk Syndromes, their families, health practitioners. With the collective dedication of all involved, PREVENTABLE stands on the cusp of reshaping the future of RTRS care.



### 3. Follow us on social media

Stay ahead with the latest advancements, contribute to the dialogue on rare diseases, and join a global community dedicated to transforming healthcare. By following us on social media, you become an integral part of our mission to prevent advanced diseases in families affected by RTRS.



**Website** : [Preventable.eu](https://Preventable.eu)  
**LinkedIn** : [Preventable\\_EU](https://Preventable_EU)  
**Twitter** : [@Preventable\\_EU](https://@Preventable_EU)  
**Youtube** : [Preventable\\_EU](https://Preventable_EU)  
**Instagram** : [@preventable\\_eu](https://@preventable_eu)

**THANK YOU!**



# Preventable

SUSTAINABLE CARE FOR RARE TUMOR RISK SYNDROMES

## Contact info

Project Coordinator:  
Carla Oliveira

Project Manager:  
Sara Pereira

i3S – Institute for Research and Innovation in Health, University of Porto

Rua Alfredo Allen 208  
135-4200 Porto, Portugal

Tel.: +800 408 220 351 (national landline call)

Email: [preventable@i3S.up.pt](mailto:preventable@i3S.up.pt)

## Subscribe newsletter

[Subscribe](#)

## Disclaimer

This project is funded by the European Union under the Grant Agreement n° 101095483. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or HADEA. Neither the European Union nor the granting authority can be held responsible for them.

