



European network for Gynaecological Rare Cancer research: From Concept to Cure

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Rare Gynaecological Cancers Are Common

Approximately 18.5 million women annually are affected by gynaecological cancer, of which around 50% are classified as rare cancers.



Delayed Diagnosis Leads to Poor Outcome

Delayed diagnosis of patients suffering from rare gynaecological cancers leads to poor outcomes and contributes to a huge socio-economic burden.

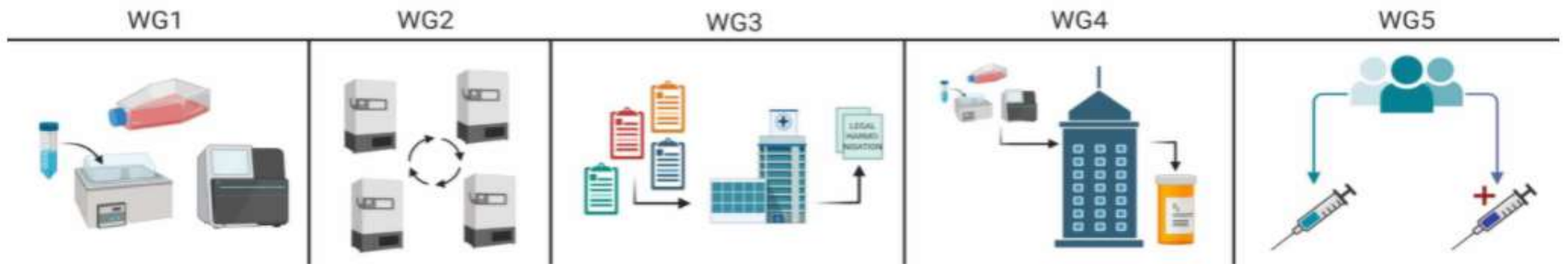




Aims

Unique network between key stakeholders covering five distinct domains:

- **WG1:** Basic research on rare gynaecological cancer
- **WG2:** Biobanking
- **WG3:** Legal and regulatory issues
- **WG4:** Industrial dimension to bridge the gap between translational research and pharmaceutical/biotechnology companies
- **WG5:** Designing high-quality, international, and innovative clinical trials





Why CA18117 was timely?

- The EU Mission on Cancer, which is part of the Horizon Europe research and innovation programme for the years 2021-2027
- Europe's Beating Cancer Plan is a political commitment to turn the tide against cancer in the EU
- European Reference Networks (ERNs): The first 24 ERNs launched in 2017
- ORPHANET - the portal for rare diseases and orphan drugs; and ORPHAcodes, supported via the RD Code project (2019-2021)
- The legislation for medicines for rare diseases and for children was evaluated in 2020, and an impact assessment for revision of the legislation is currently ongoing
- The Clinical Trials Directive has been repealed by the Clinical Trials Regulation which became applicable on 31 January 2022



Focus on:

- capacity-building on rare gynaecological cancer by connecting high-quality scientific communities in various disciplines, existing networks, policy-makers, industrial partners, and patient organisations across Europe and beyond;
- coordinating, and contributing to the development of a research roadmap dedicated to connect innovative basic research to harmonised biobanking to 'smarter' clinical trials;
- the development of a platform for sharing best practices, including funding roadmap and legal/ethical requirements, in rare gynaecological cancers, aiming to advice policy-makers and other key stakeholders;
- providing equal networking opportunities for early-stage researchers, and other talented young professionals.



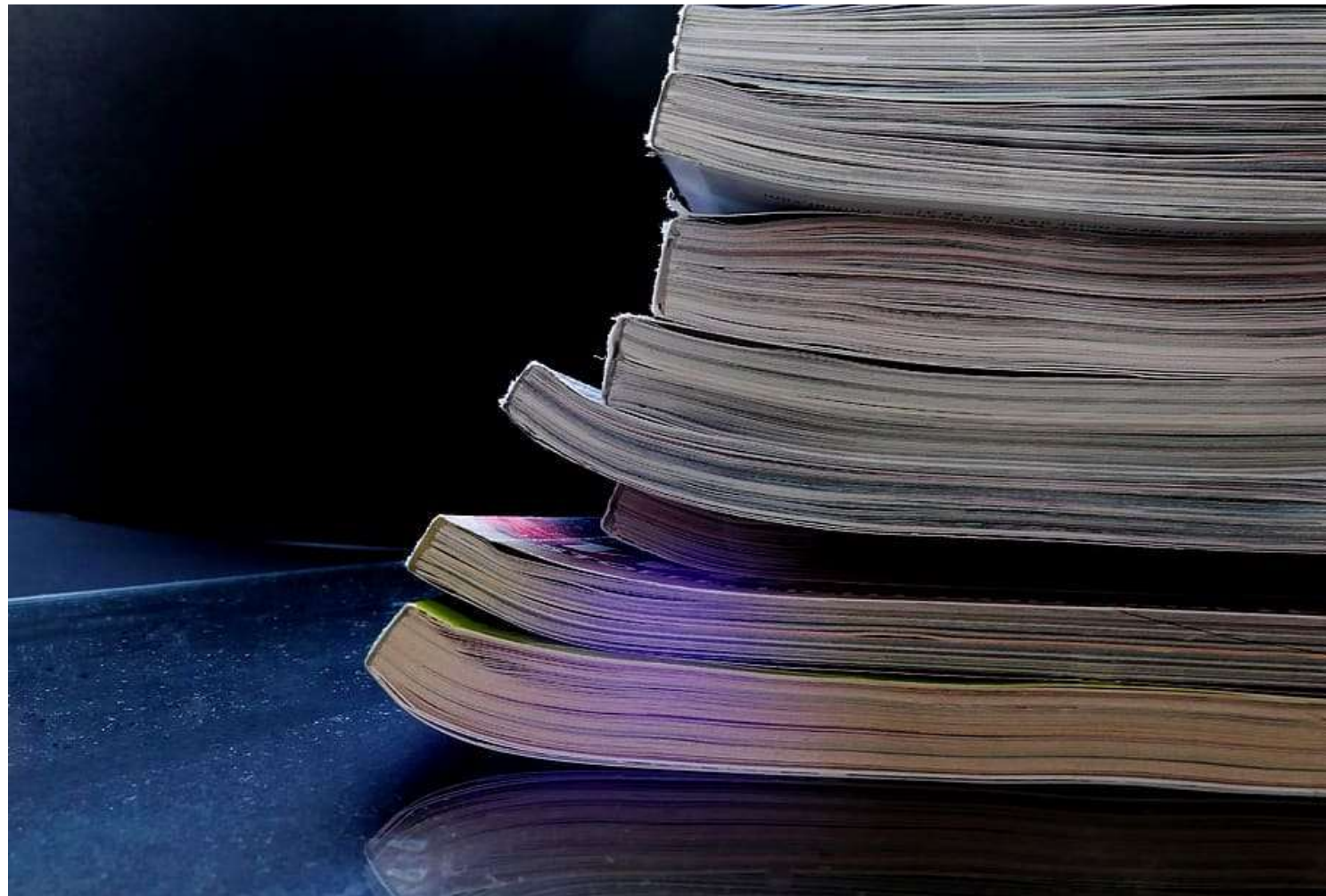
What has CA18117 achieved?

- 40 open access scientific publications with multiple co-authors
- Special Issue in the European Journal of Surgical Oncology
- Update of the international reference textbook on rare and uncommon gynae cancers (Springer)
- 4 book chapters, 1 patent on a surgical instrument
- 3 international conference (Malta, Italy, Bulgaria): over 250 attendees in total
- 2 Training Schools (North Macedonia, Bulgaria): over 200 attendees in total
- Involvement of Policy Makers, including President of EU Parliament
- Multiple press conferences and news items on national TV, radio and other media portals in different languages
- Masters, PhDs, Career advancements, Promotions to Professorship
- 6 STSMs, 14 Virtual Mobilities, 3 dissemination grants, ITC conference grant
- Achievement of outcomes beyond the agreed deliverables (eg collaboration with NASA space agency)
- International Award for Professionalism in Medical Ethics and Research given to the Chair
- More information on the permanent website: www.gynocare.net



Open access Publications & Resources

Freely available on
www.gynocare.net



GYNOCARE Conferences and Training Schools





Article

GYNO CARE Update: Modern Strategies to Improve Diagnosis and Treatment of Rare Gynecologic Tumors—Current Challenges and Future Directions

Riccardo Di Fiore ^{1,2}, Sherif Suleiman ¹, Bridget Ellul ³, Sharon A. O'Toole ⁴, Charles Savona-Ventura ⁵, Ana Felix ⁶, Valerio Napolioni ⁷, Neil T. Conlon ⁸, Ilker Kahramanoglu ⁹, Miriam J. Azzopardi ¹⁰, Miriam Dalmas ¹¹, Neville Calleja ¹⁰, Mark R. Brincat ¹², Yves Muscat-Baron ¹², Maja Sabol ¹³, Vera Dimitrievska ¹⁴, Angel Yordanov ¹⁵, Mariela Vasileva-Slaveva ¹⁶, Kristelle von Brockdorff ¹⁷, Rachel A. Micallef ¹⁷, Paul Kubelac ^{18,19}, Patriciu Achimas-Cadariu ^{19,20}, Catalin Vlad ^{19,21}, Olga Tzortzatou ²², Robert Poka ²³, Antonio Giordano ^{2,24}, Alex Felice ²⁵, Nicholas Reed ²⁶, C. Simon Herrington ²⁷, David Faraggi ²⁸ and Jean Calleja-Agius ^{1,*}



International Journal of
Molecular Sciences



Review

Extraterrestrial Gynecology: Could Spaceflight Increase the Risk of Developing Cancer in Female Astronauts? An Updated Review

Rosa Drago-Ferrante ^{1,†}, Riccardo Di Fiore ^{2,3,†} , Fathi Karouia ^{4,5,6} , Yashwanth Subbannayya ⁷ , Saswati Das ⁸, Begum Aydogan Mathyk ⁹, Shehbeel Arif ^{10,11} , Ana Paula Guevara-Cerdán ¹², Allen Seylani ¹³, Aman Singh Galsinh ¹⁴ , Weronika Kukulska ¹⁴, Joseph Borg ¹⁵ , Sherif Suleiman ², David Marshall Porterfield ¹⁶ , Andrea Camera ¹⁷ , Lane K. Christenson ¹⁸ , April Elizabeth Ronca ^{19,20}, Jonathan G. Steller ^{21,22} , Afshin Beheshti ^{23,24,*}  and Jean Calleja-Agius ^{2,*} 



Stakeholders involved

- Clinicians: oncologist, gynaecologists, pathologists, paediatricians, surgeons, physicians, radiologists, etc
- Nurses, Radiographers, Medical Physicists
- Academics and Researchers, PhD and Masters students, medical students and students from allied health
- Lawyers
- Ethicists
- Biomedical engineers
- Biostatisticians and Epidemiologists
- Public Health Experts
- Policy Makers and Politicians
- Pharmacists and the Pharma and Biotech Industry
- Experts in the Clinical Trials Regulation
- Patient Advocacy Groups – national and EU (eg EUROPADONNA, ESGO-ENGAGE)
- Journalists and media experts



Who are we?

200+ members from:

- Belgium
 - Italy
 - Ireland
 - France
 - Greece
 - Hungary
 - Israel
 - Moldova
 - Montenegro
 - Netherlands
 - Norway
 - Spain
 - UK
 - USA
 - Tanzania
 - Bhutan
- Inclusiveness Target Countries**
- Malta
 - Albania
 - Bulgaria
 - Croatia
 - Cyprus
 - North Macedonia
 - Turkey
 - Portugal
 - Romania
 - Poland
 - Bosnia and Herzegovina
 - Slovenia
 - Montenegro
 - Serbia
 - Latvia





Problems encountered

- Almost all the MC members were **new to COST** - this was one of the first actions on women's health, not focused on pregnancy
- Most members were **hands-on practicing healthcare professionals**, during the time of the COVID-pandemic
- There was an **entire change in the leadership roles** within the MC after the end of Year 1, without handover from the previous Chair and WG leads
- Even the **new website** had to be done from scratch!
- The **new Chair and leadership roles had to be assigned** at a time when we had to be online as it was not possible to travel due to the COVID pandemic
- For the **first kick-off in October 2021** with the new Chair, there only 9 participants from a total of 4 countries
- The **first face-to-face hybrid meeting was held in May 2022**, more than halfway through the project.
- Through the VMs, collaborative publications, the 6-month extension from COST , we managed to achieve all the deliverables, and more by the **end of the project in October 2023!**



How COST funding helped in advancing knowledge & research on rare gynae cancer

- Gave opportunity for health care professionals, academics and patients hailing from under-resourced areas, region and countries, who are not normally given a voice (for example Eastern Europe, where there is a higher incidence of cervical cancer and poor access to screening and prevention)
- Multi- and interdisciplinary collaborations between different healthcare professions, and other professions such as lawyers, ethicists, biotech and pharma experts, and biomedical engineers
- Open access publications and resources, as well as attendance to high quality international conferences and training schools
- Empowering patient advocacy groups in matters related to informed consent, biobanking and clinical trials
- Informing policy makers on cancer prevention, screening, early diagnosis and access to proper management



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Thank you for making the impossible, possible!



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Website: www.gynocare.net