Tamara Hussong Milagre je ustanoviteljica in predsednica združenja bolnikov EVITA - Cancro Hereditário (= AVOID Hereditary Cancer), ki od leta 2011. podpira družine, prizadenete z dednimi rakavi obolenji. Od leta 2017 je predstavnica Evropske zagovorniške skupine za bolnike pri Evropski referenčni mreži GENTURIS (Sindromi genetskega tveganja za tumorje), kjer sodeluje v skupini HBOC o dednem raku dojk in raku jajčnikov ter v delovni skupini za izobraževanje, usposabljanje in razvoj.

Aktivno se ukvarja z raziskavami raka. Poleg dodatnega izobraževanja je leta 2017 opravila program na Evropski šoli za onkologijo ESO za vodilne zagovornike pacientov, kasneje pa se je v študiju EUPATI izobraževala o pomenu in vplivu vključenosti pacientov v raziskave in razvoj zdravila. Leta 2019 je diplomirala na EURORDIS Leadership School on Healthcare & Research, programu za krepitev zmogljivosti za evropske skupine za zagovarjanje pacientov (ePAG) na področju vodenja, zdravstvenega varstva in raziskav pri upravljanju omrežij.

Tamara redno sodeluje s portugalsko agencijo za zdravila Infarmed in je vključena v Evropsko federacijo farmacevtskih industrij in združenj EFPIA, in sicer projektu onkološke platforme "Čas za dostop do bolnika". Vodi delovno skupino za dedna rakava obolenja pri portugalskem združenju za onkologijo. Je članica več svetovalnih odborov, kot je denimo skupine Misija rak Portugalska pri AICIB, Inštituta za z dokazi podprto zdravje ISBE, vodi pa tudi mednarodne delovne skupine za razsejani rak dojk in dedne rake. Redno sodeluje kot predavateljica na nacionalnih in mednarodnih konferencah, povezanih z zdravjem, in je v stalnem stiku s tisoči nosilcev genov po vsem svetu, saj je članica in svetovalka v več mednarodnih zaprtih skupinah na družbenih omrežjih, od katerih ima ena več kot 10.000 članov.

Novembra 2020 jo je portugalski minister za znanost odlikoval medaljo za znanstvene dosežke.

Tamara Hussong Milagre is the founder and president of the patient association EVITA – Cancro Hereditário (=AVOID Hereditary Cancer), supporting families affected by Hereditary Cancer Syndromes since 2011. Since 2017, she is also a European Patient Advocate Group representative at European Reference Network GENTURIS (Genetic Tumor Risk Syndromes), compromised in the thematic group about Hereditary Breast and Ovarian Cancer HBOC and in the taskforce for Education, Training and Development.

She is actively involved in cancer research. Besides further education, she performed in 2017 the Master Class of the European School of Oncology ESO for leading patient advocates and turned later into a Patient Expert by undergoing the EUPATI course which taught her the importance and impact of patient involvement in the research and development of medicines. She graduated in 2019 from EURORDIS Leadership School on Healthcare & Research, a capacity building programme for European Patient Advocacy Groups (ePAGs) on leadership, network management healthcare and research.

Tamara collaborates on a regular bases with the Portuguese medicines agency Infarmed and she is involved in the European Multi-Stakeholder Sounding Board of EFPIA Oncology Platform | "Time to Patient Access" Project. She integrates the working group dedicated to Hereditary Cancer Syndromes of the Portuguese Society of Oncology. She is member of several advisory boards, p.eg. the advisory group of the Cancer Mission Portugal by AICIB, the advisory board of the Institute of EVIDENCE BASED HELATH ISBE and integrates international working groups regarding metastatic breast cancer and hereditary cancer. She is a frequent invited speaker on national and international health related conferences and is in constant contact with

thousands of gene carriers all over the world by being a member and counselor of several international closed groups on social media (one of which > 10.000 members).

In November 2020 she received the Medal of Scientific Merit from the Portuguese Minister of Science.