

Dear BECA Committee members, Dear European Commission,

We, civil society, patient and professional organisations, industry and other stakeholders working in breast cancer welcome the European Commission's ambitious Europe's Beating Cancer Plan and the European Parliament's Special Committee on Beating Cancer (BECA) efforts and commitment in delivering a comprehensive strategy to fight cancer.

Nevertheless, we as breast cancer stakeholders across different sectors would like to raise our deep concern by the fact that the BECA report and suggested amendments do not reflect the special attention that **advanced/metastatic cancer** deserves. This is especially concerning, in light of the ongoing pandemic, that as we know has already caused severe disruption in screening and consequently increased late-stage diagnosis that is already presenting as a big challenge for the healthcare sector and will continue to be in the coming years. We were saddened to see that advanced/metastatic cancer is mentioned solely in the context of palliative care, when therapeutic innovations have increased the survival time of advanced/metastatic cancer patients. As a consequence and though advanced breast cancer remains mostly incurable, patients live on average between 3 and 5 years (in some subtypes, more and more patients can live up to 10 years with advanced/metastatic breast cancer) and have specific needs. As such, we urge the Committee to consider the specific needs of patients with late-stage or metastatic cancer.

In light of the consideration of the BECA's draft report, we as the breast-cancer community, urge the BECA Committee as well as the European Commission's DG SANTE Cancer Team to consider a multitude of special needs of advanced and metastatic cancer patients:

- > Leveraging the European Commission's European Health Data Space, TBCT believes that there should be a harmonised breast cancer registry process in Europe for collecting breast cancer data, including both early and metastatic breast cancer. Currently, most European cancer registries do not collect data on relapse and therefore, we do not know how many Europeans are living with metastatic cancer.
- > The quality of cancer care is of utmost importance. To achieve this, breast cancer patients should be treated in accredited centres by a multidisciplinary and specialised team. In this context, it is pivotal that Comprehensive Cancer Centres across the EU are equipped and ready to address the specific needs of breast cancer patients including advanced and metastatic breast cancer patients.

- > We urge for more attention to be dedicated to improving the quality of life of patients and their families, with a special attention for those with advanced/metastatic disease and terminal conditions. Currently, no cure is known for advanced breast cancer, but therapeutic advances allow patients with metastatic forms of cancer to live longer lives. Often, the disease affects women in the prime of their lives when they have both career and childcare responsibilities. Due to continuous treatment, these patients face severe long-term symptoms, such as fatigue, cognitive and memory problems and peripheral neuropathy. Quality of life is thus the biggest area of unmet need and access to care is very important to patients living with advanced metastatic breast cancer.
- > Advanced communication skills should be an essential component of healthcare provider education programs in different languages for all HCPs caring for patients with metastatic cancer. We urge for policymakers to drive change in the common perception of advanced cancer, from a "death sentence" to a condition with which patients can survive for a prolonged period of time with a relative good quality of life and a productive life.
- > As the stigma and isolation has become a reality for most metastatic cancer patients, it is critical to ensure that the general public is educated on the disease.
- > Lastly, it is pivotal to make sure that adequate support and help is provided to patients with metastatic cancer patients to continue to work. This can be done by implementing legislation that protects their right to work and guarantees flexible and accommodating workplace environments that take into consideration the effects and the special needs of the patients.

The signatories of the letter (listed below) call on the EU to ensure that needs of metastatic/advanced cancer patients are at the forefront of Europe's Beating Cancer Plan and express their interest to collaborate with the European Commission, the Parliament and Member States to ensure that the gaps in metastatic breast cancer care are adequately addressed.

Sincerely,

Fatima Cardoso, on behalf of



Cristina Fernández, on behalf of



Paraskevi Mihalopoulou, on behalf of



Catiana Martínez, on behalf of



Maricarmen Bonafonte, on behalf of



Renate Haidinger, on behalf of



Shirley Bianca L. Müseler, on behalf of



Dr. Assia Konsoulova, on behalf of



Nicoleta Antone, on behalf of



Anja Skjoldborg
Hansen, on behalf of



Krisztina Tóth, on behalf of



Antonella Cardone, on behalf of



Sonia Ujupan, on behalf of



Fatima Cardoso, on behalf of



Isabel Rubio, on behalf of



Isabel Rubio, on behalf of



Marzia Zambon, on behalf of



Cezar Irimia, on behalf of



Antonia Gimón, on behalf of



Carole Terrasanta, on behalf of



Màrius Soler Bosch, on behalf of



Ivana Cattaneo, on behalf of



Prof. Rossana Berardi, on behalf of



Ana Tecic Vuger, on behalf of



Mihaela Geoana, on behalf of



Sebastian Arias, on behalf of



Matthijs van Meerveld, on behalf of



Mariajosé Oráa, on behalf of



Dr Nicolò Matteo Luca Battisti, on behalf of



Almenka Balenović, on behalf of



Frances Fitzgerald, MEP, on behalf of



Prof. Rossana Berardi, on behalf of



Barbara Wilson, on behalf of

