ABC GlobAlliance
An ESO initiative

# ABC GLOBAL CHARTER 2018

European School of Oncology
learning to care

The ABC Global Alliance
is an ESO initiative

# INTRODUCTION

The ABC Global Charter has been developed to address the most urgent and actionable gaps in treatment and care of patients with advanced breast cancer (ABC) to ultimately improve and extend their lives. The ABC Global Alliance, an ESO (European School of Oncology)-backed multi-stakeholder platform initiated in November 2016, will drive forward the ABC Global Charter and encourage the worldwide breast cancer community, policy makers and the public to work together to help change the future of patients with ABC around the world.

**ALMOST 50% OF BREAST CANCER CASES AND 58% OF DEATHS OCCUR IN LESS DEVELOPED COUNTRIES**

**IN MEN, THE DISEASE IS MUCH RARER, BUT TENDS TO BE MORE ADVANCED WHEN DETECTED COMPARED TO WOMEN**

The ABC Global Alliance is a platform for all those interested in collaborating in common projects relating to ABC. Our goal is to improve and extend the lives of women and men living with ABC in all countries worldwide and to fight for a cure. We will also raise awareness of the disease in the broader cancer community and beyond, with particular emphasis on the global health and development stakeholders to lobby worldwide for the improvement of the lives of patients with ABC.

Despite significant progress in the management of early breast cancer (EBC), major gaps still exist in the treatment and management of ABC and median survival has remained stubbornly stuck at 2 to 3 years after diagnosis of metastases. Although breast cancer is thought to be a disease of the developed world, almost 50% of breast cancer cases and 58% of deaths occur in less developed countries. Breast cancer is the top cancer in women worldwide and is increasing particularly in developing countries where the majority of cases are diagnosed in late stages, underscoring the urgent need to address gaps in current care. Metastatic disease may occur at diagnosis (called "de novo") or as a relapse sometime after a diagnosis of early breast cancer; in the developed countries de novo ABC represents only about 10%, while in developing countries it reaches 60 or 80% of new breast cancer cases. Even with the best available therapies, about one third of breast cancer cases diagnosed early will eventually relapse and become ABC. Although breast cancer is more common in women, men are also affected. In men, the disease is much rarer, but tends to be more advanced when detected, compared to women.

The ABC Global Charter addresses gaps in care, access to resources and support, and treatment outcomes for patients with ABC, as identified in the Global Status of Advanced/ Metastatic Breast Cancer 2005-2015 Decade Report. Research from the Count Us, Know Us, Join Us has found that patients with ABC feel isolated from the established 'pink' breast cancer movement which tends to focus on prevention and survivorship. In contrast, the ABC Charter aims to drive change in the care of patients with ABC, tailoring actions to make them relevant and feasible for different geographies and capacities. The Actions for Change aim to achieve near and longer-term goals, to give patients a voice, bring patient needs to the fore for driving decision-making and ultimately improve and extend their lives.

*Advanced Breast Cancer (ABC) comprises inoperable Locally Advanced Breast Cancer (LABC) and Metastatic Breast Cancer (mBC). mBC is also known as stage IV or secondary breast cancer. For the purposes of this document, we use the term advanced breast cancer (ABC).*

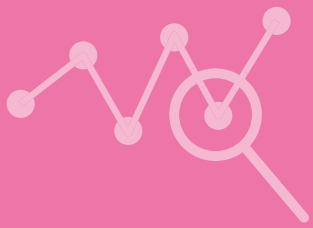
# 10 FOR 10: TEN GOALS OVER THE NEXT DECADE TO DRIVE GLOBAL IMPROVEMENTS IN ABC CARE

Our goal is to unite the ABC community by **CATALYSING CHANGE TO IMPROVE ABC PATIENT OUTCOMES**. Healthcare professionals (HCPs), governments, health policy makers, patient advocates, members of the breast cancer community, and anyone whose life is touched by ABC should unite to **TAKE ACTION** at local and international levels to help achieve the objectives described below by 2025 and in doing so ensure that advanced breast cancer patients feel included in the Sustainable Development Goals vision of "leaving no one behind".

# BACKGROUND

## KEY GAPS AND ACTIONS FOR CHANGE IMPERATIVES FOR IMPROVING ABC PATIENT CARE BY 2025

Gaps in ABC research, ABC patient care and ABC in society have been identified. The **10 ACTIONS FOR CHANGE** are designed to help address these gaps and drive improvements in care.



**PATIENT OUTCOMES AND DISEASE BURDEN:** Patient outcomes in ABC have improved minimally over the past decade, with substantial variation according to subtype of breast cancer, and there is currently no cure. Despite some advances, there is limited understanding of how to achieve disease remissions and also to improve tolerability of therapy and quality of life (QoL) for patients living with ABC. Currently, disease burden and unmet needs are difficult to measure due to widespread lack of accurate, population-based data for patients with ABC.

**PUBLIC PERCEPTION AND STIGMA:** Stigma and isolation are commonly experienced by those with ABC, highlighting a need for increased support and awareness in the broader community. The general public, though differing by country and region, has misperceptions around ABC, driven by a lack of education about the disease, the notion of survivorship in breast cancer, and scientific progress in EBC to date.

**SOCIAL AND CAREGIVER RELATIONSHIPS:** Societal understanding of ABC is limited, which can apply additional pressure to the immediate family and caregivers of patients, who have deeper understandings of the patient experience. This increased burden, specifically on caregivers, results in emotional, financial, professional and practical unmet needs.

**ADVOCACY INITIATIVES:** Many patient support organizations include patients with ABC in their care and outreach. Despite recognition of the greater needs of patients with ABC compared to those with EBC, too few organizations are able to secure adequate resources to support ABC-specific initiatives and policies.

**WORKPLACE INITIATIVES:** Despite willingness and financial pressures to return to work, patients with ABC often do not receive recognition or the opportunity for adequate adjustments within the workplace. Many employers have limited understanding of the specific needs and impact of ABC, which result in insufficient support for their ABC employees during diagnosis and treatment. Most patients with ABC are forced to leave or adapt their professional activity.

**POLICY:** ABC has been and will continue to be associated with a significant economic burden to society and healthcare systems. Despite this, there remains limited ABC-focused policies to drive improved levels of cost-effective and quality care.

**PATIENT CARE CONTINUUM:** Comprehensive care gaps exist in breast cancer centers along the care continuum, from diagnosis through to end of life. Improvements in supportive care services, such as psychosocial care and access to multidisciplinary teams, are needed.

**HEALTHCARE PROVIDER COMMUNICATION AND SUPPORT:** There is a lack of ABC-specific training and educational materials to support HCPs engaging in a two-way dialog with patients. This limits conversations around diagnosis, treatment decisions, disease progression and end of life, leaving people with ABC unprepared for what lies ahead.

# 10 ACTIONS FOR CHANGE

1

## HELP PATIENTS WITH ABC LIVE LONGER BY DOUBLING ABC MEDIAN OVERALL SURVIVAL BY 2025

- There has been limited improvement in patient outcomes in ABC over the past decade, and the burden of disease is expected to continue to rise.
- All patients with ABC must be treated by a multidisciplinary, specialized team, and according to high quality international/national guidelines.
- Policy environment should allow access for all patients with ABC to the best available therapies and to supportive/palliative measures.
- Dedicated and coordinated research is needed specifically focused on ABC.
- The patient voice needs to be included (via experienced patient advocates) in the design of clinical trials and development of clinical registries/criteria.

2

## ENHANCE OUR UNDERSTANDING ABOUT ABC BY INCREASING THE COLLECTION OF HIGH QUALITY DATA

- Generally, cancer registries around the world only collect information about initial cancer diagnoses and mortality; most do not document cancer recurrences that represent the majority of ABC cases and therefore it is currently unknown how many patients with ABC exist.
- Readily accessible, good-quality data at the time of ABC progression, recurrence, and survival (i.e. of robust epidemiology and outcomes data for ABC) are urgently needed and can be useful for shaping policy decisions.
- Provide guidance and input to help establish uniformity of the ABC data collection.
- Increase knowledge about ABC by developing and implementing robust Big Data (Analytic) systems/processes, around the world.
- Include the patient voice (via experienced patient advocates) in the design of clinical trials and development of clinical registries/criteria.

## 3 IMPROVE THE QUALITY OF LIFE (QOL) OF PATIENTS WITH ABC

- Improve the wellbeing of patients living with ABC by raising awareness about the need to collect and act upon quality of life data.
- Limited utilization of QoL tools in clinical practice can be partially attributed to a non-standardized definition of QoL and inadequate measurement tools for advanced and metastatic patients. Increased focus on development and implementation of ABC-specific QoL measurement tools in clinical practice and policy making is essential to improve QoL and care of patients with ABC.
- Systematically include QoL, PROMs (patient-reported-outcomes) and PREMs (Reported Experience Measures) in clinical research to understand patient perspective of living with ABC and the burden of treatment.
- QoL should encompass physical, social, and emotional well-being including relationships, supporting the need for a holistic and multidisciplinary approach to care.
- Patients input regarding what type of QoL issues to measure, respecting geographical and cultural differences, should be sought.
- Empower patients to raise QoL expectations and discuss this with their healthcare professionals as well as their treatment

## 4 ENSURE THAT ALL PATIENTS WITH ABC RECEIVE THE BEST POSSIBLE TREATMENT AND CARE BY INCREASING AVAILABILITY OF AND ACCESS TO CARE FROM A MULTIDISCIPLINARY TEAM

- Patients with ABC require access to multidisciplinary clinical care and specialists to improve treatment, outcome and overall QoL.
- Support should differ from that for early breast cancer (EBC) patients, particularly regarding types of available information.
- Increase availability and access to multidisciplinary care, including palliative, supportive, and psychosocial assistance for patients, families, and caregivers to ensure patients are receiving the best treatment experience.
- The development of access to remote multidisciplinary tumour boards is essential for patients living in a long distant from all major care centres.
- Ensure that each patient with ABC has access to a "key contact" who is also a member of the multidisciplinary team and who coordinates their care throughout the care continuum, including when elements of that care take place outside the specialist breast unit/centre.
- A range of materials should be available and tailored to meet patients' specific needs and to empower patients when making treatment decisions; support should be offered to patients when reviewing the content.
- Gaps in support for sexual health and relationships should be acknowledged and addressed.
- Address the needs of families and caregivers in a culturally sensitive way, including the needs of children, adults including spouses, siblings, parents and non-related caregivers.

5

## IMPROVE COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS (HCP) AND PATIENTS WITH ABC THROUGH THE PROVISION OF COMMUNICATION SKILLS TRAINING FOR HCPS

- Advanced Communication skills should be included as an essential component of healthcare provider education programs for all HCPs caring for patients with ABC including at medical school core curriculum level. The new ESMO-ASCO Global Oncology Curriculum should be implemented in all countries.
- Within communication training programs, there should be an emphasis on ensuring that HCPs understand what matters to patients and carers in order to support and guide them through treatment decisions.
- Learnings can be drawn by HCPs from other advanced and some chronic diseases to drive change in patient perception of ABC – from that of a death sentence to a condition with which patients can live for a prolonged period of time. There is a need to validate the effectiveness of education and communication tools in different languages.

6

## MEET THE INFORMATIONAL NEEDS OF PATIENTS WITH ABC BY USING EASY TO UNDERSTAND, ACCURATE AND UP-TO-DATE INFORMATION MATERIALS AND RESOURCES

- Increase access to existing materials for those seeking them rather than creation of new ones; increase networking and sharing of best practice examples between organisations.
- Materials should be focused on messages most relevant to patients with ABC, such as patients' fears of pain and uncertainties about their disease and its outcome. Materials should assist patients in the decision-making process, including addressing individual patient needs.
- It is critical that resources in low- and middle-income countries are explicit in what treatments are available to patients specifically in their own. However, information should also be provided on treatments available in other countries, to allow patients to access these if they are able.

7

## ENSURE THAT PATIENTS WITH ABC ARE MADE AWARE OF AND ARE REFERRED TO NON-CLINICAL SUPPORT SERVICES

- Outside of clinical care, patients are often unaware of available services, such as local volunteer/advocacy organizations, to assist with daily activities and living. Awareness of these services should be raised, and patients referred to them as appropriate.
- Policies are needed to help minimize access barriers to supportive services and assist in efficiently connecting patients to the services they need.
- Increased access to and provision of non-medical patient navigators and care coordinators is needed to help patients understand services available and what they are entitled to receive, as well as to facilitate access to and increase uptake of those services required.

8

## COUNTERACT THE STIGMA AND ISOLATION ASSOCIATED WITH LIVING WITH ABC BY INCREASING PUBLIC UNDERSTANDING OF THE CONDITION

- The stigma and isolation felt by patients with ABC can be attributed to limited understanding of the disease by the general public.
- There is a need to educate the general public on what the terms “advanced breast cancer” and “metastatic” mean. Education is needed to highlight that patients can live with the disease while also transparently conveying the truth, particularly around the median overall survival.

9

## ENSURE THAT PATIENTS WITH ABC HAVE ACCESS TO TREATMENT REGARDLESS OF THEIR ABILITY TO PAY

- Strive for all patients with ABC to have financial support for treatment, care and assistance if unable to work.
- Provide a mechanism to avoid financial catastrophe in the event that patients lose employment.
- Work to ensure that patients with ABC have or maintain health coverage, even if unemployed.
- Support access to treatment regardless of the ability to pay, through policy and accountability mechanisms.
- Work to ensure patients have access to additional financial support where needed e.g. for childcare, transport to access their treatment.
- Support patients with financial advisory services, empowering them to better manage their finances throughout treatment.

10

## HELP PATIENTS WITH ABC CONTINUE TO WORK BY IMPLEMENTING LEGISLATION THAT PROTECTS THEIR RIGHT TO WORK AND ENSURES FLEXIBLE AND ACCOMMODATING WORKPLACE ENVIRONMENTS

- Many patients with ABC want or need to continue working through their diagnosis and treatment; however, there are very few policies and guidelines that focus on employment during cancer treatment for metastatic disease.
- Most patients with ABC are not protected in the workplace and are often denied employment flexibility to deal with effects of the disease and its treatment. In addition, patients with ABC may face discrimination based on disease misperceptions.
- Protection against discrimination should come from individual employers and the employment system and patients should be empowered through provision of information and knowledge to request support and protection.

# DEVELOPMENT OF THE ABC GLOBAL CHARTER

An earlier collaboration between ESO and Pfizer led to the development of the preliminary mBCVision2025 'Call-to-Action'. This important work has been taken forward by the multi-stakeholder ABC Global Alliance to become the ABC Global Charter. The content for the Call-to-Action was determined by consensus from mBC Vision 2025 Taskforce members. Following an open consultation process to gain feedback and input into the Global Charter from the ABC community, the ABC Global Alliance Interim Steering Committee revised and finalised the ABC Global Charter. The Charter has been revised in 2018 for better wording and clarification and approved by the ABC Global Alliance Executive Committee.

*The ABC Global Charter has been developed to unite the ABC community to drive action and help us to work together towards common, achievable goals. Work is now underway to implement the Actions for Change, ultimately to improve and extend the lives of patients with ABC.*

**REFERENCES**


1. Cardoso F, Costa A, Norton L, et al. ESO-ESMO 2nd international consensus guidelines for advanced breast cancer (ABC 2 Published simultaneously in: Breast. 2014;23(5):489-502; Ann Oncol. 2014;25(10):1871-1888.
2. World Health Organization. Projections of mortality and causes of death, 2015 and 2030. http://www.who.int/healthinfo/global_burden_disease/projections/en/. Updated July 2013. Accessed August 2017.
3. Global Status of Advanced/Metastatic Breast Cancer: 2005-2015 Decade Report. http://breastcancervision.com. Published March 2016. Accessed August 2017.
4. Cardoso F., Spence D., Mertz S., Corneliussen-James D., Sabelko K., Gralow J., Cardoso MJ., Peccatori F., Paonessa D., Benares A., Sakurai N., Beishon M., Barker SJ., and Mayer M.. Global Analysis of Advanced/Metastatic Breast Cancer: Decade Report (2005–2015). The Breast 39: 131-138, 2018.
5. Metastatic Breast Cancer Network. 13 facts about metastatic breast cancer. http://mbcn.org/images/uploads/13_Facts_about_Metastatic_Breast_Cancer2014.pdf. Accessed August 2017m

# CONTRIBUTORS TO THE ABC GLOBAL CHARTER

## ABC GLOBAL ALLIANCE EXECUTIVE COMMITTEE
**(DECEMBER 2017-DECEMBER 2019)**

**F. Cardoso**,
Champalimaud Clinical Center, Lisbon, PT ***(Chair)***

**M. Aapro**,
Genolier Cancer Centre, Genolier, CH

**M. Hurlbert**,
BCRF and MBC Alliance, New York, US

**R. Kaur**,
Breast Cancer Welfare Association Malaysia (BCWA), Petaling Jaya, MY

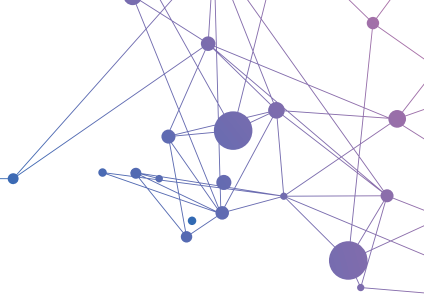
**M. Pandeloglou**,
Breast Cancer Network Australia (ABC patient representative), AU

**D. Spence**,
Breast Cancer Network Australia, Camberwell, AU

**M. Thrift-Perry**,
Pfizer Inc., New York, US

**J. Torode**,
Union for International Cancer Control, Geneva, CH

**T. Wiseman**,
European Oncology Nursing Society, London, UK



# ABC GLOBAL ALLIANCE INTERIM STEERING COMMITTEE
## (NOVEMBER 2016-NOVEMBER 2017)

**F. Cardoso**,
Champalimaud Clinical Center, Lisbon, PT (Chair)

**B. Aguilar Lopez**,
Breast Cancer Advocate, Mexico City, MX

**G. Cook**,
Novartis Parmaceuticals Corp., East Hannover, US

**R. Haidinger**,
Brustkrebs Deutschland, Hohenbrunn, DE

**M. Hurlbert**,
BCRF and MBC Alliance, New York, US

**S. Knox**,
Europa Donna – The European Breast Cancer Coalition, Milan, IT

**M. Thrift-Perry**,
Pfizer Inc., New York, US

**J. Torode**,
Union for International Cancer Control, Geneva, CH

**M. Ziv**,
Israel Cancer Association, Givatayim, IL

# MBC VISION 2025 TASKFORCE MEMBERS

**F. Cardoso**, Champalimaud Clinical Center, Lisbon, PT ***(Chair)***

**M. Aapro**,
Genolier Cancer Centre, Genolier, CH

**B. Aguilar Lopez**,
Breast Cancer Advocate, Mexico City, MX

**B. Anderson**,
Fred Hutchinson Cancer Research Center, University of Washington School of Medicine, Washington, US

**A. Cabanes**, Susan G. Komen, New York, US

**I. Chitapanarux**, Chiang Mai University, TH

**K. Crawford-Gray**, Worldwide Breast Cancer, Lewisville, US

**V. Diéras**, Institut Curie, Paris, FR

**A. Dvaladze**,
University of Washington, US

**N. El-Saghir**,
Naef K. Basile Cancer Institute at the American University of Beirut Medical Center, Beirut, LB

**S. Gupta**,
Tata Memorial Centre, Mumbai, IN

**K. Holm**,
Patient Advocates for Cancer Research & Treatment, Geneva, CH

**M. Hurlbert**,
BCRF and MBC Alliance, New York, US

**G. Lopes**,
Oncoclinicas do Brasil Group & Sylvester Comprehensive Cancer Center at the University of Miami, BR

**M. Mayer**,
AdvancedBC.org, New York, US

**G. Nakigudde**
Uganda Women's Cancer Support Organization, Kampala, UG

**C. Nolan**,
Breast Cancer Network Australia, Camberwell, AU

**O. Olopade**,
University of Chicago, US

**H. Rugo**,
UCSF Helen Diller Family Comprehensive Cancer Care, US

**K. Sabelko**,
Susan G. Komen, US

**D. Schmitt**,
Stiftung Path Breast Cancer Biobank, Konstanz, DE

**E. Schumacher-Wulf**,
Mamma Mia! Breast Cancer Magazine, Kronberg, DE

**D. Spence**,
Breast Cancer Network Australia, Camberwell, AU

**C. Taylor**, Global Focus on Cancer, Port Chester, US

*Global Status of Advanced/Metastatic Breast Cancer 2005-2015 Decade Report Steering Committee member

# SPONSORS

The ABC Global Alliance is sponsored through unrestricted grants provided by:

## MAIN SPONSORS

AstraZeneca

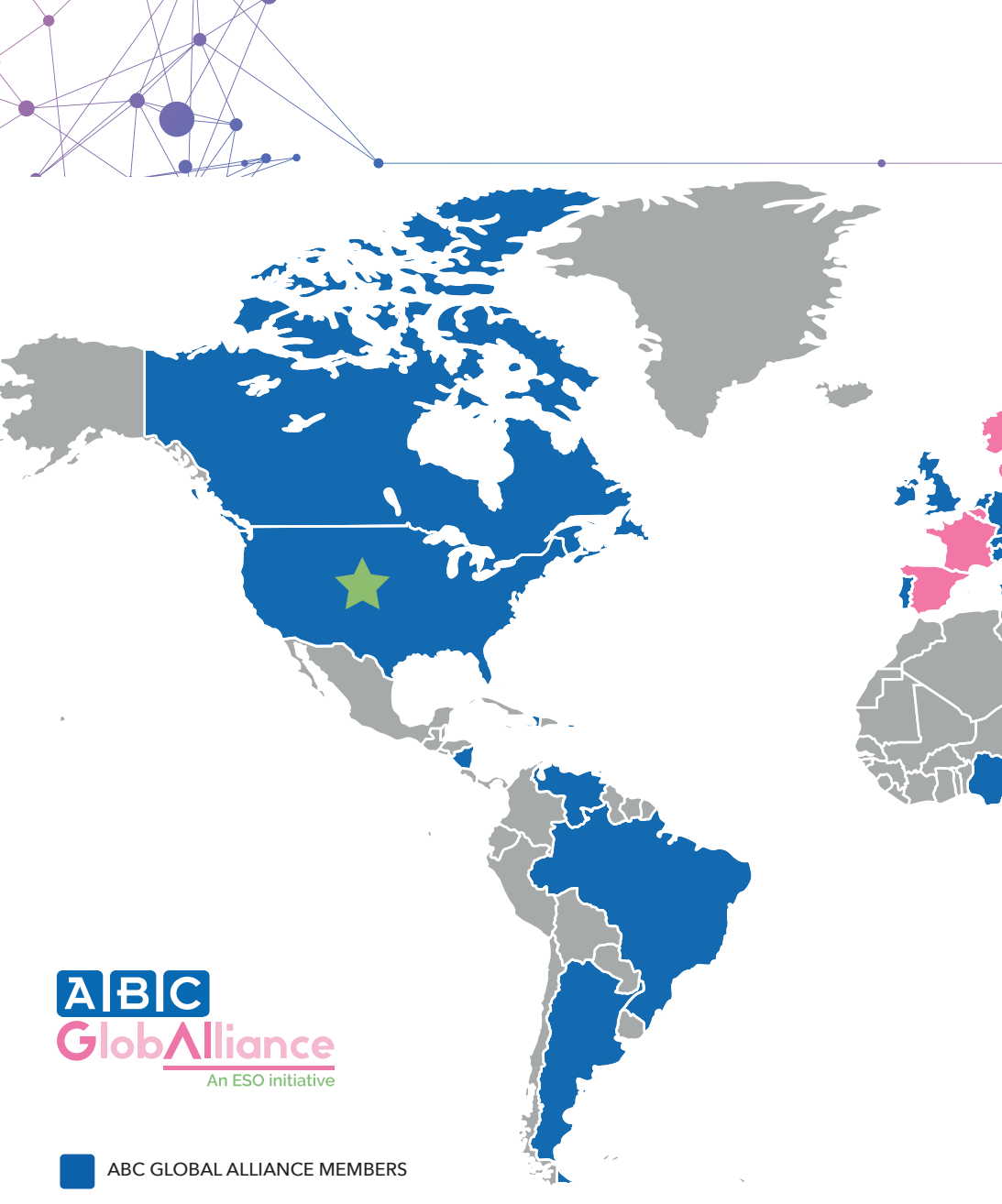
Bristol-Myers Squibb

Lilly | ONCOLOGY

NOVARTIS

Pfizer Oncology

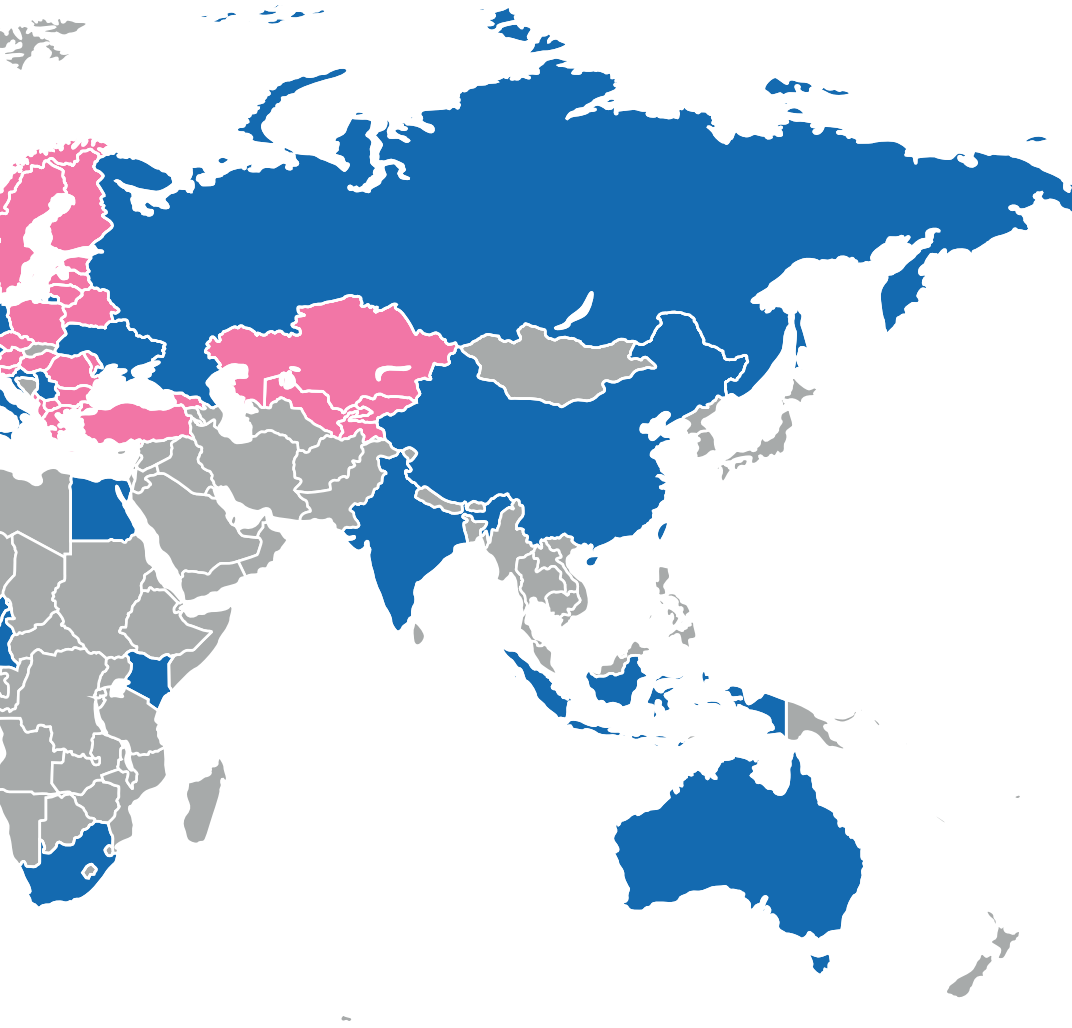
**The ABC Global Alliance is an ESO initiative**




ABC GLOBAL ALLIANCE MEMBERS

MEMBERS REPRESENTED THROUGH EUROPA DONNA - THE EUROPEAN BREAST CANCER COALITION (full list of countries available at www.europadonna.org)

MBC ALLIANCE REPRESENTS ALL ITS MEMBERS IN THE ABC GLOBAL ALLIANCE (full list of members available at www.mbcalliance.org)



AS OF 1ST JUNE 2018

ABC GlobAlliance
An ESO initiative

**www.abcglobalalliance.org**


## ESO

**ESO Milan**

Via Turati, 29
20121 Milan – Italy
Phone: +39 02 8546451
Fax: +39 02 85464545

**ESO Bellinzona**

Piazza Indipendenza, 2
6500 Bellinzona – Switzerland
Phone: +41 91 8200950
Fax: +41 91 8200953

## FURTHER INFORMATION

**Roberta Ventura**
ABC Globa Alliance Managing Coordinator

Email: ABCGlobalAlliance@eso.net
Phone: +41 91 8200 956


## FOLLOW US ON

*All rights reserved. Printed in Italy, June 2018*