



# Advanced breast cancer advocacy goes global

The advanced breast cancer community has spent many years defining the treatment, care and support patients need to help them live longer and feel and function better. They've now formed an alliance to advocate for those needs to be met across the globe. **Marc Beishon** reports.

A generation ago, stigma surrounding breast cancer – whether early or advanced – was widespread across the globe. It was the advocacy movement that changed this, forcing policy makers and the public to confront an illness that had been largely hidden and that struck mainly women, who are at the heart of family life and caregiving in most countries – and increasingly often the primary breadwinner.

Yet the early advocacy and patient groups by and large failed to challenge the stigma associated with a metastatic breast cancer diagnosis. The later stage of the disease that kills

didn't fit with the mood of optimism and hope attached to the pink campaigns and early stage breast cancer groups. Women with advanced cancer found that their needs and concerns were not being addressed either by support groups or, to large extent, by healthcare professionals.

The past 10 years has seen a steady uptick in focus on the unmet needs of people with metastatic breast cancer (mBC), which have grown all the more urgent due to the stalling progress in survival. Milestones include the ABC consensus meeting on advanced breast cancer, launched by the European School of Oncology

(ESO) in 2011 ([www.abc-lisbon.org](http://www.abc-lisbon.org)); the publication of the 'Global status of advanced/metastatic breast cancer 2005–2015 decade report' ([bit.ly/decade\\_report](http://bit.ly/decade_report)); and most recently the establishment of the ABC Global Alliance ([www.abcglobalalliance.org](http://www.abcglobalalliance.org)), another ESO initiative, which draws together organisations with interests in advanced breast cancer, and which will elect its first steering committee members at ABC4 in Lisbon in November 2017.

These efforts have made an impact. The metastatic breast cancer population is now widely recognised as a distinct group with specific needs.

Those needs have been researched and documented (although few countries know how many people are living with the disease, as the information is not collected by cancer registries). A wide range of these issues was publicised in the ‘Decade report’ and in the Here and Now campaign ([www.wearehereandnow.com](http://www.wearehereandnow.com)), and now the ABC Global Alliance has set out a Global Charter of 10 achievable and measurable actions for the next 10 years – which the advanced breast cancer community is united to fight for. They will address public perception and stigma, social and caregiver relationships, healthcare provider communication, advocacy, national policy and more.

Not least is the need to make much greater progress on survival from scientific and clinical research – while there are new agents and approaches in the pipeline, advances are slow and have limited benefits. The aim is to double median survival from the current two to three years, up to four to six years by 2025.

But there is much to gain from raising the quality of treatment and care across the world to current standards by applying the multidisciplinary recommendations issued by the bi-annual ABC consensus conference. As medical oncologist Fatima Cardoso, who is the force behind the ABC ‘movement’ and initial chair of the Alliance, says: “If all patients had access to everything we already have, we would cut breast cancer mortality by 30%. But the ultimate goal of the charter is to improve both survival and quality of life, and there are more ways to do this than just through science.”

What is needed now is to spread the charter’s messages to as wide an audience as possible, while being mindful of resource constraints, and

## The ABC Global Charter: 10 actions for change



The ABC Global Charter lists 10 actions that are priorities for change, which are listed below. The full wording, which will be available on the Alliance website – [www.abcglobalalliance.org](http://www.abcglobalalliance.org) – explains and expands on the actions. It also includes a list of key gaps and imperatives that inform the actions for improving ABC (advanced breast cancer) patient care by 2025.

1. Double median overall survival for patients with ABC to at least four years by 2025.
2. Improve quality of life for patients with ABC in clinical practice.
3. Improve availability of robust epidemiology and outcomes data for ABC.
4. 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.
5. Strive for all patients with ABC to have financial support for treatment, care and assistance if unable to work.
6. Offer communication skills training to all healthcare providers.
7. Provide accurate and up-to-date ABC-specific information tools to all patients who want them.
8. Increase public understanding of ABC.
9. Improve access to non-clinical supportive services for ABC.
10. Protect workforce rights for patients with ABC.

to advocate for resources to address the unmet needs that have been so thoroughly researched and defined. That is what the ABC Global Alliance aims to do.

### A global alliance of activists

“The Alliance brings together people and organisations across the world who want to work together to change the lives of people with advanced breast cancer for the better,” says Alberto Costa, CEO of the European School of Oncology. “In recent years the ABC consensus meeting has become a magnet for people who

want to contribute to defining the best standards of treatment and care for patients with advanced breast cancer. For ESO, launching an alliance aimed at making those standards a reality across the globe seemed an obvious next step.”

The Alliance’s interim steering committee includes representatives from advocacy groups such as Europa Donna, Breast Cancer Network Australia and the Metastatic Breast Cancer Alliance (which represents groups in the US, where the advocacy movement has the longest history), as well as representatives from industry and from the Union for International Cancer

### Harmonising the terminology

Secondary? Advanced? Metastatic?  
Metastatic? Secondary?  
Advanced? Metastatic?  
Secondary? Advanced?  
Metastatic? Secondary?

Part of the problem about breast cancer communication and awareness is terminology. In cancer generally, it is not uncommon for patients to come away from a consultation having understood the opposite of what their oncologist meant – ‘inoperable’ does not mean ‘untreatable’, and ‘progression’ does not mean that a treatment is working. In some countries, ‘secondary’ has been used to describe metastatic breast cancer, but the term is confusing, as it can also be used to denote a recurrent, non-metastatic cancer, and not all metastatic breast cancers are relapses, as they can be diagnosed at this stage (*de novo* mBC). It also does not convey the same sense of seriousness as the term ‘metastatic’.

Danielle Spence says Breast Cancer Network Australia, with the help of the ABC community, has decided to stop using the term ‘secondary’ to avoid confusion, and also because ‘metastatic’ is the term used in the great majority of material that people search for on the Internet. “We found it was causing confusion for women with early breast cancer who had experienced a second primary, and was also not resonating with our members who had *de novo* disease,” says Spence. The UK, the other notable English-speaking country that still uses ‘secondary’, may well follow suit, though some research has shown that patients prefer to use ‘secondary’.

The term ‘advanced’, meanwhile, is often taken as interchangeable with ‘metastatic’, but there is an important distinction. ‘Advanced’ includes two clinical entities: metastatic disease, which means the cancer has spread to distant sites; and locally inoperable breast cancer, which is characterised by large tumours in the breast and lymph nodes but no distant spread. The Advanced Breast Cancer (ABC) consensus conference covers both stage III (inoperable) and stage IV (metastatic) breast cancer. While with optimal treatment stage III has a much better relative survival rate than stage IV, there are also significant unmet needs and complexity among these patients that warrant inclusion in the consensus.

For most of the world, ‘metastatic’ is the key term, but confusion about what it means and its implications is widespread.

Control (UICC). Elections at ABC4 will continue this ‘multistakeholder’ approach, and the new committee will set out priorities for the next two years – certainly advocacy and policy

work will be to the fore, as the Alliance aims to give countries support in meeting their biggest concerns.

Danielle Spence, policy and advocacy director at Breast Cancer

Network Australia (BCNA), says support for those with metastatic disease had not been emphasised in the past as much as it should have been but, after researching needs, her organisation has begun to remedy this. “We have redesigned our key resource – Hope & Hurdles – to better meet the needs of people with metastatic breast cancer. We were sending this to 1,000 women a year who are newly diagnosed, but we hope to double that. Lack of information and awareness are big barriers, and many find a diagnosis overwhelming, so we have an introductory guide that leads into more detailed information about subtypes, so that people can personalise what they need. We are also raising the profile of mBC issues whenever we can, such as by running dedicated workshops at events.”

Awareness of the different facets of the disease needs much promotion, adds Spence. “For example, many people don’t realise that there are often long periods of wellness as well as illness during treatment, which itself can be long-term.” This has direct impact on other issues such as work and financial concerns, and healthcare organisation. In Australia, says Spence, her group has helped to change government policy to release retirement funds to people with a life expectancy of two years, instead of one, and currently is advocating for specialist nurses, or care coordinators, to help people with metastatic breast cancer to navigate the health and welfare systems.

“Metastatic patients enter the system in a different way to those with early stage breast cancer, and women are telling us that many nurses just don’t have an understanding of the metastatic pathways, which often involve more community-based care,”

she says. Having all patients with metastatic disease discussed in a multidisciplinary team meeting is another issue Spence highlights.

A topic that is contentious in many nations is currently being debated in Australia – end-of-life care and right to die legislation. “We surveyed 11,000 BCNA members, including about 500 with metastatic cancer, and about 80% of those with metastatic breast cancer and 75% of those with early disease support assisted dying legislation. It’s one of the subjects I’ll be talking about at ABC4.”

As Spence adds, these issues are typical around the world, and having standards set by the Global Alliance can play a crucial role when writing to ministers about, say, lack of specialist nurses, or reform of welfare conditions. “Having a framework we can quote is great,” she says.

In the US, Susan G. Komen, or Komen for short, is one of largest breast cancer advocacy organisations. Kim Sabelko, who heads scientific partnerships and programmes, says while it has been a long journey to overcome the stigma of breast cancer generally, “in the US there has been progress in how we talk about the disease and how it is detected, diagnosed and treated. However, we still have over 40,000 women and men dying of metastatic breast cancer each year, and more than 154,000 people living with metastatic disease in the US,” she says. “That’s not OK, and so the battlefield is shifting to focus more on metastatic breast cancer.”

As in Australia, there is a knowledge gap to address with resources and local meetings, and in the US the financial burden of having advanced disease can be great. “We are fighting this disease on all fronts

– providing accurate, evidence-based information about metastatic breast cancer to empower patients and their caregivers; offering support through local meetings, our breast cancer helpline and treatment assistance programme, for example; advocating for policies to ensure mBC patients can afford and have access to timely and quality care; and funding research to discover how to treat and prevent metastasis and bring an end to this disease,” says Sabelko. A blog on the extensive Komen website carries patient perspectives, which the organisation aims to weave into everything it does, she says.

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Komen works at an international level too, as Anna Cabanes, global programmes director, comments. It has a particular focus on low-income countries, where it supports education and cancer control projects to increase capacity to address breast cancer.

It is capacity that is badly needed, she argues: “About 80% of breast cancer in sub-Saharan Africa is diagnosed at advanced stages and even 30–48% in a country such as Brazil. There is perhaps more fear about seeing doctors than stigma against the disease, and we feel there is an opportunity to promote awareness of all stages of breast cancer at once, rather than going through the long

‘early to metastatic’ route that the US and other developed countries have done.”

Cabanes says the issues she sees are women left unprotected by welfare systems and cumbersome bureaucracy, and lack of access to some standard treatments, even in countries with universal healthcare systems. “There’s a lot of fragmentation – you could have one treatment, but not the next one, as it’s not offered.”

Both Cabanes and Sabelko are involved in the Global Alliance. “What I like is that it is truly global – it’s inclusive of all economies and settings,” says Cabanes. “It could have much impact where there is lot of metastatic cancer, although it will be challenging given that a lot of issues are related to healthcare systems.” Sabelko adds that it is important to bring organisations together to focus on metastatic breast cancer, to better highlight issues that would not otherwise come in front of policy makers, and also to pool resources – Komen does not want to duplicate work that other agencies are doing, she says. “There is also great power in patient voices to demand access to care and funding for research.”

One country where Komen works is neighbouring Mexico. Bertha Aguilar, an advocate in Mexico who was diagnosed with early-stage breast cancer at the age of 30, and is a member of the Global Alliance interim steering committee, says she became involved in ‘pink’ campaigns in her country, but felt they didn’t do enough advocacy to help patients, and particularly women with metastatic breast cancer, some of whom are as young as she was when diagnosed.

Aguilar is a patient advocate and advisor for MILC ([milc.org.mx](http://milc.org.mx)) and

### Join the ABC Global Alliance!



The ABC Global Alliance is for people and organisations who are committed to developing, promoting and supporting tangible improvements that will ultimately create awareness and actions that will improve and extend the lives of patients living with ABC worldwide.

To apply for membership go to the Partners and Supporters page of [www.abcglobalalliance.org](http://www.abcglobalalliance.org) or contact Roberta Ventura at [ABCGlobalAlliance@eso.net](mailto:ABCGlobalAlliance@eso.net)

Salvati ([salvati.org.mx](http://salvati.org.mx)), both non-governmental organisations that are tackling access and treatment issues for mBC, and have representation in several parts of Mexico. “We have big problems with obtaining treatment – there can be waits of months – and in rural communities there can be long distances to travel to see an oncologist, and you won’t get an income if you don’t work,” she says.

### There does now seem to be real impetus behind change for the care of people with advanced breast cancer

There is a negative attitude expressed around the world, she adds, with people questioning why women who are going to die should receive costly treatment. “Women are learning that they should be on certain medicines, but they only get what the system has, which is often for early-stage breast cancer,” she

says. “It means we have to demand better quality of life for women and help them prepare for what’s to come, as some will be thrown out of their jobs.”

Building public understanding of breast cancer and issues such as workplace rights is crucial and very much the domain of the Global Alliance, Aguilar adds. “Governments that see what other countries are doing are more likely to find the money.”

Advocacy must, however, be tailored to local conditions, as Aguilar and colleagues found out at another advocacy group, Cimab Foundation, which won a grant from the UICC and Pfizer to develop Internet resources for the metastatic population, in 2015.

“We thought the Internet would help, but we have found that women in rural communities are often afraid to use it. So we are also working with hospitals to train people as patient navigators, who can help fill information gaps and create care plans.”

Online resources do work well in other settings, however. Europa Donna, the coalition of European breast cancer advocacy groups, ran its first metastatic advocacy

conference in June 2017, and has launched an mBC website, with resources including an advocacy toolkit and patient videos. These initiatives build on Europa Donna’s longstanding support for the Alliance and the ABC conference and its efforts to get governments to address unmet needs, not least by promoting the 2015 European Parliament Declaration on the Fight Against Breast Cancer.

That Declaration made specific demands for patients with mBC, calling on member states to ensure they have access to a specialist breast unit that coordinates care and psychosocial needs.

Marie Pandeloglou, an Australian advocate with metastatic cancer, attended the Europa Donna meeting on behalf of BCNA. “The issues raised by the global advocates are not dissimilar to the challenges Australians living with mBC face – wondering how we are expected to cope with the anxiety, uncertainty, depression, and losing control of our bodies as part of the disease process,” she says. “There is a great sense of agreement that people need encouragement, support and empowerment, help in dealing with side-effects of treatment and help with financial stress.”

It’s been a long time coming, but there does seem now to be a feeling of real impetus behind change for the care of people living with advanced breast cancer.

Not everyone in the breast cancer movement always agrees on the best steps to take next, of course, but as Komen’s Cabanes says, it is only by “putting our collaborative hats on” that progress can be made.

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