HAVING THEIR SAY Patient advocates (from left): Maggie, April, Mairead and Adrienne

Banking on your support

ALWAYS PUTTING PATIENTS FIRST

Breast Cancer Campaign's Tissue Bank patient advocates explain why donating breast cancer tissue to research could be the key to solving the breast cancer puzzle

For many people whose lives have been touched by breast cancer, the knowledge that scientists are racing to find a cure gives them something positive to focus on.

Until recently, however, scientists were only able to work on artificially grown breast cancer cells, which do not always accurately represent how real breast cancer cells behave.

That all changed in 2011, when Breast Cancer Campaign created its pioneering Tissue Bank. For the first time researchers had access to real breast cancer tissue, generously donated by patients. This tissue is vital in improving our understanding of the disease – leading to more reliable results and, hopefully, treatments tailored to individuals.

But many patients are unaware their tissue could be used in research, making every sample that is donated to the Tissue Bank precious. This is why the Tissue Bank's Access Committee and Management Board, which oversees the Tissue Bank, asked a group of patient advocates to help put breast cancer patients at the forefront of the Tissue Bank's work.

Each advocate became involved following their own diagnosis with breast cancer, and although it hasn't been easy, patient advocacy is a chance for them to have a say in the future of breast cancer research.

Maggie Wilcox and Dr Adrienne Morgan have both been involved with the Management Board, and played an important role when it came to helping review research centres applying to be Breast Cancer Campaign's Tissue Bank.

'There were several very good applications,' says Adrienne, who was first diagnosed with breast cancer in 2005, aged 49. 'So rather than picking one existing tissue bank, we suggested to the Management Board that a few of them should collaborate.'

And they did. The Tissue Bank is based in four leading research institutions: Barts Cancer Institute, Queen Mary University of London; the University of Nottingham; the University of Dundee, and the

University of Leeds. Each one collects and stores high-quality breast tissue samples.

It's the role of the Tissue Bank's Access Committee to allow scientists to use the samples, and the patient advocates help review applications, ensuring there are rigorous procedures safeguarding the tissue and the patients who donate it.

'Breast tissue is valuable and must be treated with care and respect,' says Mairead MacKenzie, who became a Campaign patient advocate following treatment for ER+, HER2+ breast cancer, including a mastectomy and reconstructive surgery. 'If we do not see the benefit in a piece of research, we have to say so.'

First-hand experience of the disease also helps advocates raise awareness of tissue donation. 'Patients should be encouraged to donate, and information should be available to explain what happens to their tissue,' says April Matthews,

"BREAST TISSUE IS VERY VALUABLE TO RESEARCH AND MUST BE USED WITH CARE AND RESPECT"

- Mairead MacKenzie, Tissue Bank patient advocate

who was diagnosed back in 2001 and invited to join by Maggie. Fellow advocate Jacqui Gath (not pictured) adds: 'It's important that patients know what projects their tissue will be used for, and if there will be any benefits. That way they know their tissue won't be wasted.'

In the future, the advocates would like to see the Tissue Bank collecting samples from all stages of breast cancer, from diagnosis to post-mortem tissue, and hope that researchers around the world will also have access to the samples.

'My cancer has returned, so it's incurable,' says Adrienne. 'Progress in research may not help me, but for others the Tissue Bank is the single most important development to help speed up research.'

COMING SOON...
GAP ANALYSIS FINDINGS REVEALED

After the success of the first Gap Analysis in 2006, Campaign will publish the findings of the five-year follow-up this autumn. Gap Analysis will continue to shape the future for women with breast cancer, and transform their diagnosis, treatment and quality of life.

WHAT IS THE GAP ANALYSIS?

The Gap Analysis is a series of vital meetings with 107 world-renowned breast cancer scientists to identify the gaps in our knowledge of breast cancer, and to discuss what should be done to keep research moving forwards.

One of the most important outcomes of the last Gap Analysis was the Breast Cancer Campaign Tissue Bank, the UK's first nationwide resource to provide access to real breast tissue samples, which scientists need to produce more reliable results and translate research quickly and effectively to benefit patients.

WHY IS IT SO VITAL?

Around 50,000 women in the UK are diagnosed with breast cancer each year, and 12,000 still die from the disease. Since the early 1980s, breast cancer cases have increased by nearly 60 per cent in the UK, with more women than ever diagnosed each year.

Our Chief Executive, Baroness Delyth Morgan, says: 'Significant progress has been made but there are critical gaps in research, and opportunities for research breakthroughs are still being missed. Gap Analysis sees international scientists across the UK joining forces to overcome barriers and speed up the path to a cure.'

WHAT'S NEXT?

This autumn we are calling for supporters to get involved with Gap Analysis so we can continue to support women with breast cancer and beat the disease.

For more info, visit breastcancercampaign.org