Patient Advocacy

Ann McBrien

Why Being Counted Matters:

How Research Became a Platform for Change for People Living with Secondary Breast Cancer

Cancer Focus
NORTHERN IRELAND

Why Being Counted Matters: How Cancer Focus NI Research Became a Platform for Change for People Living with Secondary Breast Cancer

One year on from the launch of groundbreaking research funded by Cancer Focus Northern Ireland and made possible thanks to a kind donation from the late Dr Jim Birnie and his family, patient advocate Ann McBrien reflects on the journey that helped shine a light on secondary or metastatic breast cancer and turn data into a catalyst for change.

For years, people living with secondary breast cancer were largely invisible in cancer statistics, policy discussions, and service planning. The research funded by Cancer Focus NI changed that by counting, for the first time, how many people in Northern Ireland are living with metastatic breast cancer.

Image 1: Ann McBrien pictured at the 2024 European Society of Medical Oncology (ESMO) Breast Cancer conference.

This pioneering work created a platform that has already begun to influence awareness, advocacy, research, and policy.

As the old saying goes, ‘success has many fathers, whilst failure is an orphan.’ When progress finally happens, many voices and organisations rightly share in the achievement. But the truth is that change often begins with just a few determined individuals who refuse to accept the status quo. At the heart of that change is the story of one patient determined to ensure that people living with secondary breast cancer would no longer be overlooked.

From early diagnosis to a life-changing reality

Ann McBrien was diagnosed with early-stage breast cancer in 2013 at the age of fifty through the breast screening programme. The tumour was extremely small. She underwent breast-conserving surgery, radiotherapy, and endocrine treatment. Five years on from the original diagnosis Ann was discharged and considered cured. However, just two months later, after an MRI for shoulder pain, she was diagnosed with metastatic breast cancer.

“It was an incredibly traumatic time,” she recalls. “My world was turned upside down as I tried to understand what it meant to have a terminal illness.”

Like many patients, Ann began searching for information to help make sense of her diagnosis and find some hope for the future. Instead, she discovered something startling.

People who have a cancer recurrence are not counted in cancer statistics or registries.

“In today’s world we count everything, from money to calories to the steps we take every day,” she says. *“So, it was hard to believe that people like me simply weren’t counted.”*

As a former Health Trust accountant, Ann immediately understood the implications.

“If you’re not counted, you’re not recognised. And if you’re not recognised, services, support and research aren’t properly resourced.”

Turning advocacy into research

Determined to change that, Ann began campaigning alongside fellow patient advocate Julie Lillis.

Their message was clear: **data could change lives.**

The breakthrough came when they met with Cancer Focus Northern Ireland. The charity's CEO, Richard Spratt, listened carefully to their concerns and recognised the significance of the issue.

The charity helped provide a platform for their voices and, crucially, secured funding for the research to address the data gap.

Image 2: Ann McBrien and Julie Lillis pictured at the announcement of NI's first secondary breast cancer research audit alongside Richard Spratt, CEO at Cancer Focus NI and Dr Damien Bennett from the NI Cancer Registry.

The study was carried out by the Northern Ireland Cancer Registry and involved analysing thousands of records to estimate the number of people living with metastatic breast cancer and those newly diagnosed each year.

For Ann, being involved in the research team was deeply meaningful.

"It meant the patient voice was at the centre of the work," she says.

Researchers worked tirelessly, manually reviewing records to produce the data.

"They understood how important this research was, not just for me, but for every patient living with metastatic breast cancer."

The results were published in JAMA Network Open - a leading international medical journal, placing Northern Ireland among the first countries in the world to produce estimates of the number of people living with metastatic breast cancer.

But the most important outcome was not the publication. It was the **platform for change** that the research created.

From research to action and international recognition

By establishing reliable data for the first time, the research gave advocates and policymakers something they had never had before - evidence.

That evidence has already helped drive several important developments.

- It has raised awareness of secondary breast cancer
- It has strengthened calls for improved services and support
- It has created new opportunities for research and clinical trials
- And it has placed Northern Ireland at the centre of international conversations about metastatic breast cancer.

The research has been recognised globally. Ann was invited to present the work at the European Society of Medical Oncology International Breast Cancer conference and the Advanced Breast Cancer (ABC) Global Alliance conference. The research has also been included in the ABC Decade Report highlighting major advances in metastatic breast cancer care across the world over the previous ten years.

"It was incredible to see the work recognised internationally," she says. *"But what mattered most was that patients living here were no longer invisible, they mattered, and they could drive change."*

Driving policy change

The research has also helped shape discussions around cancer services in Northern Ireland.

When the findings were presented at Stormont in March 2025, Ann alongside Cancer Focus NI called for the development of a dedicated **metastatic breast cancer pathway**.

Such a pathway would establish best practice and ensure consistent care across Northern Ireland regardless of where a patient lives.

Image 3: Ann McBrien pictured at the launch of Cancer Focus NI's secondary breast cancer audit at Stormont in March 2025.

The Health Minister committed to developing this pathway as part of the Review of Breast Services. Although the work has not yet begun, the commitment itself demonstrates the influence of the research.

"It shows what can happen when you have the evidence," Ann says. *"The research has given us a platform to push for change."*

Changing the conversation around metastatic breast cancer

Beyond policy, the research has helped transform how metastatic breast cancer is viewed. For many years the disease was rarely talked about publicly, and patients often felt isolated.

"When I was first diagnosed, I didn't know anyone in the same position and that was very difficult," Ann says.

But the research showed that around **1,000 people in Northern Ireland are living with metastatic breast cancer.** That knowledge alone has helped reduce stigma and build community. Support services have also expanded significantly. When Ann first began campaigning there was just one support group in Belfast. Today there are numerous groups across the region. Charities and patient organisations have also developed dedicated resources and programmes to support people living with secondary breast cancer.

"We are now visible and our needs are starting to be discussed and addressed," Ann says.

Progress in treatment

There has also been encouraging progress in treatments. When Ann was first diagnosed with metastatic disease her oncologist told her about the benefits of research and that new therapies might become available as advances are made.

That prediction has proved correct. In recent years many new targeted therapies have been introduced, including treatments which target brain metastases. These developments mean that many people are now living longer with metastatic breast cancer.

But Ann is clear that challenges remain. For some patients, particularly those with aggressive forms of the disease such as triple-negative, outcomes are still poor.

“Medical advances are helping many of us,” she says. *“But there are still groups of patients who urgently need more research.”*

Living with the disease

Living with metastatic breast cancer involves more than medical treatment. A separate piece of research across the island of Ireland has found that **87 per cent of patients experience mental health challenges.**

“It’s something you live with every day,” Ann explains.

Access to psychological support remains limited in Northern Ireland compared with other regions. She believes this must change if patients are to receive truly holistic care. Another priority is empowering patients to advocate for themselves.

“There is a growing movement encouraging patients to understand their disease and contribute to decisions about their care,” she says.

A legacy that continues to shape change

The research also stands as a legacy to the patients who fought to make it happen.

Julie Lillis, who campaigned alongside Ann for the collection of metastatic breast cancer data, died just one month after the research was launched. The study was dedicated to her memory. Many other patients who supported the campaign are also no longer here to see its impact.

“This research is their legacy,” Ann says. *“It is making a difference for patients today and those who will come after us.”*

What happens next?

Ann believes the next step is simple but crucial: using the data to improve services.

Key priorities include:

- Developing the metastatic breast cancer care pathway
- Expanding specialist nursing support for secondary cancer care
- Improving access to treatments and clinical trials, including those available elsewhere in the UK
- Ensuring psychological support is available to patients and families.

She also believes similar research should now be conducted for all other cancer types.

“Every cancer patient whose disease returns should be counted,” she says.

A message of hope

Despite the challenges, Ann remains hopeful.

Support networks are growing. Treatments are improving. And patients are increasingly involved in shaping the future of cancer care. Most importantly, people living with metastatic breast cancer are no longer invisible.

Image 4: Ann McBrien pictured with international patient advocates at the 2025 Advanced Breast Cancer (ABC) Global Alliance conference.

"There are around 1,000 of us living with this disease here. Thanks to the research funded by Cancer Focus Northern Ireland, we are now counted. And being counted was the first step to change." Ann says.

To discuss public affairs or policy in more detail, contact Nora Smith, Director of Policy, Research and External Engagement on norasmith@cancerfocusni.org