A Story Half Told is an initiative by Pfizer highlighting the need to widen the conversation around breast cancer in Ireland to include metastatic disease - shining a spotlight on the need for awareness, support and care.
“I think that there’s often a tendency for those with a metastatic diagnosis to withdraw from others. They don’t want to frighten other breast cancer survivors with their diagnosis and with the realities of living with an incurable cancer. It may seem ridiculous, but there’s also often a real sense of failure, of having let people down by not ‘beating’ breast cancer”

Rhona Nally, from Dublin.

“One of the hardest parts about living with mBC is trying to tell people that I am still sick and I still have terminal cancer. It gets exhausting so I just pretend like I am okay... I have spent the time since my diagnosis searching for good support and proper clear information on mBC, travelling as far as Boston to get some help.”

Evelyn Wakefield, from Offaly.

“My family and I get strength from giving support to others, and by raising awareness for metastatic breast cancer generally. It’s important to keep busy and work towards making a difference. Access to holistic support services is vital for all women with breast cancer.”

Olive Dermody, from Galway.
FOREWORD:

AWARENESS OF EARLY BREAST CANCER IS HIGH, BUT KNOWLEDGE OF METASTATIC BREAST CANCER IS LOW

The breast cancer advocacy and awareness activities, and an abundance of education efforts, information and news coverage have made breast cancer a familiar disease. Thanks to the significant strides made in early detection, research, treatment and patient empowerment over the past 30 years, there is much progress to celebrate. Indeed, the prognosis of early-stage breast cancer has transformed as survival rates have steadily increased in Ireland.

For metastatic breast cancer (mBC), however, the narrative is markedly different. With the public breast cancer conversation focused primarily on early detection and survivorship, metastatic breast cancer patients often feel misunderstood and isolated from the larger breast cancer community.

Metastatic Breast Cancer: A Story Half Told is a global educational initiative in which Pfizer is aiming to increase understanding about metastatic breast cancer. This initiative comes at a time when leaders within the breast cancer community are acknowledging worldwide that progress in mBC has not kept pace with the evolution witnessed in managing early breast cancer.

As part of A Story Half Told – and for the first time in Ireland – we have undertaken a female-only, nationally representative survey to gauge awareness of mBC. As detailed in this report, the research highlights some worrying misconceptions. Many Irish women know little about metastatic breast cancer, including the fact that early detection does not help survival for these patients.

A Story Half Told is part of Pfizer’s ongoing commitment to support everyone living with breast cancer – a commitment that has led to, for example, supporting essential fundraising activities for the Marie Keating Foundation, as well as supporting services for patients with mBC through Europa Donna Ireland and the Irish Cancer Society.

Pfizer is committed to ongoing research in cancer and in the area of metastatic breast cancer where there remains an unmet need for innovative treatments. There are currently a number of Irish hospitals and clinicians involved in clinical trials in this area and we are also delighted to support the patient groups in this area to look at the supports that patients faced with a metastatic breast cancer diagnosis need.

Though the task is challenging, the time to take action is now in order to begin the next phase of the breast cancer movement, one where all people living with breast cancer – including those with mBC – feel equally supported. Now is a time to expand the conversation to include metastatic breast cancer.
THE CURRENT BREAST CANCER LANDSCAPE

Patients with metastatic breast cancer (mBC) face unique challenges as well as a level of isolation and helplessnessvi.

Despite advances in the treatment of breast cancer, approximately 30% of women initially diagnosed with earlier stages of breast cancer eventually develop recurrent advanced or metastatic diseaseiv. Early detection does not help survival for mBC patients and average survival is only 2-3 years – although many women can live for much longerv.

The recent Global Status of Metastatic Breast Cancer Decade Report highlights that progress in mBC has not nearly kept pace with the evolution witnessed in managing early breast cancer (eBC)ii. In addition, the report confirms the many misconceptions and misunderstandings surrounding metastatic breast cancervi.

The general public’s knowledge of breast cancer issues often comes from survivor stories by patients with early breast cancer, which receive considerable attention and ensure that breast cancer is a disease familiar to many peoplei.

In contrast, A Story Half Told reveals that there is a lack of public knowledge about mBC compared with early breast cancer, which leads to widespread misperceptions and which can have a negative impact on the lives of patients and their familiesi. Substantial resources have been directed towards breast cancer - education, research and advocacy effects, which has resulted in gains that have mainly benefited those with early breast canceri.

The goal of this report is to shed light on the challenges and gaps for patients with mBC and to inspire change within the breast cancer community and beyond, including physicians, researchers, policymakers, industry, advocates, caregivers, patients, and the public.

GENERAL PUBLIC SURVEY OUTLINE:

TESTING IRELAND’S BREAST CANCER IQ V

Breast cancer represents a significant public health burden in Ireland and across the globei. Over the last decade, substantial resources directed toward breast cancer education, research, and advocacy efforts have led to gains in detection, treatment, and outcomesi. Yet, these efforts have mainly benefited those with early breast cancer, and as a result, the need for support and treatment for people living with mBC has been left in the shadowsi.

In order to understand metastatic breast cancer patients’ broader environment, a nationally representative study was conducted amongst 1,126 Irish women aged 18+ to examine their perception and understanding of metastatic breast cancer. No previous studies have examined Irish societal awareness and comprehension of metastatic disease, making this study the first of its kind.

METHODOLOGY

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td></td>
</tr>
</tbody>
</table>

- 18-34: 20%
- 35-44: 20%
- 45-54: 20%
- 55-64: 20%
- 65+: 20%

Region: 3% (North), 24% (South), 24% (West), 10% (East)

1. [Reference]
2. [Reference]
3. [Reference]
4. [Reference]
5. [Reference]
6. [Reference]
WHAT YOU MAY NOT KNOW ABOUT BREAST CANCER BUT SHOULD

Metastatic breast cancer is the most advanced stage of breast cancer, where the cancer has spread from the breast to other parts of the body (typically the brain, lung, liver and bones)\textsuperscript{i}.

95% of Irish women believe that breast cancer can be cured if caught & treated early\textsuperscript{ii}.

Approximately 1 in 3 diagnosed with early breast cancer will eventually progress to metastatic breast cancer\textsuperscript{iv}.

Also known as Stage IV breast cancer, metastatic breast cancer is incurable – the average survival is 2-3 years\textsuperscript{iv}.

92% of women believe there have been significant advances in breast cancer treatment in the last 10 years\textsuperscript{iii}.

2-3 years

95% of Irish women believe that breast cancer can be cured if caught & treated early\textsuperscript{ii}.

One-quarter (25%) of Irish women have never heard of metastatic breast cancer\textsuperscript{ii} and a further quarter (24%) have heard the term but don’t know what it means. 28% are very familiar with the term advanced breast cancer\textsuperscript{iii}.

44% of Irish women associate the word ‘uncertainty’ with metastatic breast cancer\textsuperscript{iii}.

6 in 10 Irish women think breast cancer receives a lot of public attention – but over half (70%) say metastatic breast cancer receives little to no attention\textsuperscript{iii}.

92% of women believe there have been significant advances in breast cancer treatment in the last 10 years\textsuperscript{iii}.

28% are very familiar with the term advanced breast cancer\textsuperscript{iii}.

24% have heard the term but don’t know what it means.

25% have never heard of metastatic breast cancer\textsuperscript{ii}.
When it comes to cancer general knowledge, Irish women said they know the most about breast cancer, followed by cervical cancer (9%) and skin cancer (9%). The cancer women know least about is kidney cancer.

Almost all Irish women believe that breast cancer can be cured if the disease is caught and treated early.

When asked how much public attention mBC receives, women felt it gets less public attention than general breast cancer.

Most women feel you should perform a breast self-exam about once a month but only half of women do.
Most women feel you should perform a breast self-exam about once a month but only half of women do.

Almost all women (93%) think the main risk factor for developing breast cancer is having a family history, while 76% said a genetic predisposition is a major risk factor.

3 in 10 women said a healthcare professional has talked to them about the risk of developing breast cancer, whereas nearly 7 in 10 women said their doctor or healthcare professional has never discussed risk.

A high proportion of women (84%) know someone who has been diagnosed with breast cancer.

Of these, 64% said they know someone who has died as a result of their breast cancer.

When describing breast cancer, 60% of women associate the word ‘fear’ with the disease, 49% associate ‘uncertainty’ with breast cancer and 35% associate the word ‘courage’ with breast cancer.

However, this differs when specifically describing mBC – as 55% of women associate the word ‘fear’ with metastatic breast cancer, 46% associate the word ‘death’ with metastatic breast cancer and 44% of women associate the word ‘uncertainty’ with metastatic breast cancer.

The majority (91%) of women have not personally sought out information about metastatic breast cancer in the past 12 months. Only a small proportion (9%) have looked for information about metastatic breast cancer.


iii. Metastatic breast cancer survey, sponsored by Pfizer Oncology and conducted by iReach Insights June 2016.
