

METUPUK ANNUAL REPORT

1 APRIL 2024-31 MARCH 2025



Third Annual Report (1 April 2024 – 31 March 2025)

METUPUK (Metastatic Exchange to Unleash Power UK)

METUPUK is a UK-wide patient advocacy charity for people with metastatic breast cancer (MBC) campaigning to increase public awareness and education about MBC. We work to see better care, access to drugs and trials as well as representation of MBC patients within NHS UK, the national regulators and drug companies.

Structure

METUPUK is a Foundation Charitable Incorporated Organisation registered with the Charity Commission of England and Wales (1196494), registration date 9 November 2021, and with the Office of the Scottish Charity Regulator (SCO55472), registration date 27 June 2024.

Charitable objects (excerpt from the Charity's Governing Document dated 9 November 2021)

The relief of patients in the UK who have or are at risk of metastatic breast cancer (MBC); in particular (but not exclusively) through raising awareness about MBC by the provision of information and education, working with stakeholders to increase MBC research and access to drugs and ensuring for the public benefit that MBC patient treatment and care remains a national priority.

What the charity does:

General Charitable Purposes

The Advancement of Health or Saving of Lives

Who the charity helps:

The General Public/mankind

How the charity helps:

Provides advocacy, advice and information

Where the charity operates:

Throughout England and Wales, Northern Ireland and Scotland

Registered office 4 West End Barns, West End, Northwold, Thetford, Norfolk IP26 5NE
email: contact@metupuk.org.uk

“We need everyone’s voice to promote and create change for MBC patients. Otherwise, we will just continue to die.”



Jo Taylor BEM
January 1969 -
November 2025

METUPUK were in the process of finalising this Annual Report when we heard the news that our Founder and Chair, Jo Taylor, had died.

Jo was a tireless advocate, a fearless campaigner and a beacon of hope for all those living with MBC.

Diagnosed with primary breast cancer in 2007 and MBC in 2014, Jo dedicated her life to changing the narrative around MBC. She founded METUPUK in 2016 to show the world that people with MBC are living, thriving and worth investing in.

From her advocacy and public speaking, to the creation of the red flag signs and symptoms infographics, her work has touched countless lives both here in the UK and around the world. She undoubtedly paved the way in empowering others to find their voice.

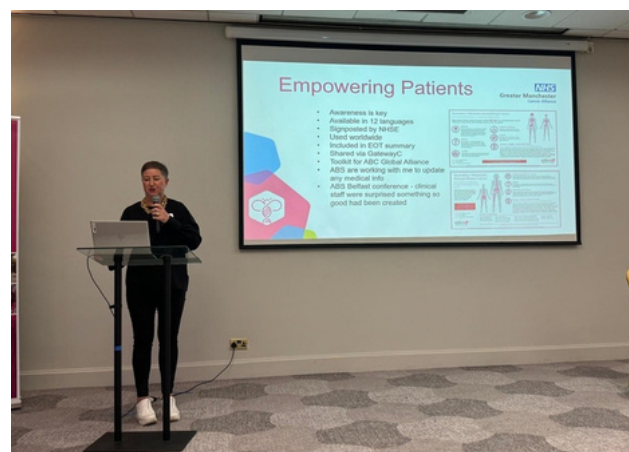
Jo championed change with unwavering resolve and spoke with unflinching honesty. Her voice lives on: her messages echo louder than ever. We demand to be counted and we demand change.

The thoughts of our Trustees and all our volunteers are with Jo’s family, friends and the entire MBC community. She will be deeply missed, but absolutely never forgotten.

She had the heart of a lioness. Rest in power Jo.

“We’re proud of what METUPUK has achieved in such a short time as a charity. Our rapid progress is down to one thing: passionate patient experts.”

Jo Taylor, METUPUK Founder and Chair



Jo Taylor speaking at the Greater Manchester Cancer Alliance Metastatic Breast Cancer conference November 2024

As we ended our second year as a Charity, we were devastated by the news that Tassia Haines, who led METUPUK’s work in Wales, had died. Most organisations would be shaken by the death of a team member but for METUPUK, this is our reality with many of our volunteers, supporters and trustees living with and dying of MBC. Spurred on with determination, May 2024 saw the launch of the Charity’s Metastatic May campaign, focussing on the “Cost of Living” (see page 12). This was set against the backdrop of the severity modifier changes facing new drug approvals, a topic that has consumed METUPUK’s drug approvals team this year.

Data has been a significant part of our focus in 2024-2025 with METUPUK on the National Audit of Metastatic Breast Cancer Advisory Group and the Patient Involvement Audit Group, ensuring the patient voice is heard. The audit has been a long time coming since it has been 12 years since data collection for MBC was made “mandatory” in England, with little data actually collected. Read more about the exceptional data progress in Northern Ireland on page 21.

Awareness is a huge issue for MBC and seeing the Charity getting the message out to the devolved nations this year has been incredible. November 2024 saw the first MBC Conference for England’s Cancer Alliances, hosted by Greater Manchester Cancer Alliance. In Wales, infographics for GPs and primary care clinicians, who play a vital role in identifying the signs and symptoms of MBC, were promoted in January 2025 at an educational event for primary care (see page 19). In Northern Ireland, METUPUK is represented on the Department of Health’s Breast Services Review.

This year, we mourn a number of volunteers and supporters who died of MBC. Their spirit and drive remain at the heart of our mission.



**EMMA LAWRENCE
(NEE FISHER)**

Volunteer
Died July 2024



LESLEY EATON

Darker Side of Pink
Died June 2024



SARAH MARSHALL

Volunteer
Died October 2024



JACQUI CREWE

Darker Side of Pink
Died January 2025

At the end of our 2024-25 financial year, our net profit was £21k. Our heartfelt thanks to all the fundraisers who keep change moving. Turn to pages 22 and 23 to see some of their amazing efforts, from skydiving to running to cycling to fun evenings, all coming together for METUPUK.

We rely on the work of our Trustees, our patient advocate volunteers and all of our supporters. None of us draw a salary from the Charity and METUPUK would not function without all the people who freely give their time and expertise. I thank everyone who has helped us become the organisation that we are today.

A handwritten signature in black ink that reads 'Jo Taylor'.

JO TAYLOR

Founder/Chair METUPUK

OUR PEOPLE



Trustees during the financial period April 2024 - March 2025 were Jo Taylor (Chair), Nicky Goldthorpe, Emma Smith, Dr Helen Steele, Laura Ashurst (appointed March 2025), Phil Southwell, Madeleine Meynell (resigned November 2024) and Andy Figgins (resigned December 2024). Current Trustees are listed on page 26.

The constitution requires at least one trustee to have MBC. New Trustees are elected by the Board where a skill shortage has been identified. Dr Helen Steele has the responsibility for the induction of new trustees, and each Trustee is provided with a copy of The Essential Trustee.



JO TAYLOR
Founder/Chair
METUPUK



NICKY GOLDTHORPE
Trustee -
Secretary



EMMA SMITH
Trustee -
Fundraising



DR HELEN STEELE
Trustee - Volunteers
and People



LAURA ASHURST
Trustee -
Darker Pink Exhibition



PHIL SOUTHWELL
Trustee -
Finance and Technology



MADELEINE MEYNELL

Trustee -

Access to Drugs

(resigned November 2024)



ANDY FIGGINS

Trustee -

Friends and Family

(resigned December 2024)

We are grateful for the outstanding impact Madeleine made during her three year tenure, advancing METUPUK's work with the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC). She now continues as our Access to Medicines Lead — see updates on page 14.

JO TAYLOR AWARDED THE BRITISH EMPIRE MEDAL

Everyone involved in METUPUK was bursting with pride at the news in late December 2024 that our founder Jo was being awarded the British Empire Medal (BEM) in the King's 2025 New Year Honours List, for her outstanding services to breast cancer patients. Jo's diagnosis of Metastatic Breast Cancer had propelled her into advocacy and in 2016 she founded METUPUK, inspired by the American group MET UP, to raise awareness and campaign for better support and visibility for people living with metastatic breast cancer.

The BEM is awarded to individuals who have made significant contributions to their community or public life, often through sustained and hands-on service. Jo's work has had a profound impact on the lives of others.



Jo Taylor BEM announced in the King's 2025 New Year Honours List.

"I'm honoured and grateful to receive the British Empire Medal. I started campaigning to make a difference so that breast cancer patients know the signs of metastatic disease, and GPs can recognise symptoms in those previously treated. My goal is simple: no one should feel uninformed or unsupported the way I once did."

VOLUNTEERS

All METUPUK's charitable activities rely on the hard work and dedication of a team of volunteers. As of 31 March 2025, 34 active volunteers from across all regions of the UK were working with METUPUK, alongside a wider network of supporters who support METUPUK by fundraising or providing campaign content or patient stories. Volunteers bring the patient voice, which is at the heart of everything that METUPUK achieves. We are extremely grateful for the passionate and tireless work of METUPUK's team of volunteers, the majority of whom are also living with metastatic breast cancer. All volunteers have been personally affected by metastatic breast cancer, either themselves or their family or friends. One of the hardest things for all involved in METUPUK is that our volunteers frequently die from MBC, reflecting the harsh reality of this disease. This year METUPUK mourned the loss of Emma Lawrence (née Fisher) and Sarah Marshall from the volunteers team.

METUPUK brings volunteers together once a year at a Strategy Weekend. It includes a review of the year as well as forward planning for campaigns and events falling in the next 12 months.

All trustees and volunteers give time freely to METUPUK. There are no paid staff, although external suppliers are used on an ad-hoc basis for policy work, website maintenance and campaigns.

A proportion of funds are spent on enabling volunteers and trustees to be efficient advocates. This includes providing all volunteers and trustees with e-mail addresses and data storage and funding patient advocates to represent METUPUK at meetings, conferences and events. See page 25 for our financial spending breakdown.



OUR AIMS AND OBJECTIVES

Our Strategy is summarised across three main areas; **Awareness and Education, Research and Access to Drugs and Patient Treatment and Care.** These were formulated with the intention of providing benefit to the public and to patients with MBC.

AWARENESS AND EDUCATION

METUPUK Aims and Objectives:

MBC is currently incurable. We highlight the harsh reality of MBC which is not well reflected in the 'pink' celebratory campaigns. Alongside increasing public awareness, we challenge and educate policy makers, charities and government bodies to ensure that MBC is a priority for funding, research and innovation. We work to ensure that MBC is represented on all Trusts or Boards of breast cancer organisations, ideally by patient advocates being included as Trustees or Board Members. We work with Cancer Alliances and Health Boards to ensure primary breast cancer patients are provided with the tools and information to understand and recognise the symptoms of MBC. This encourages earlier MBC diagnosis and earlier treatment, thereby improving quality of life and survival prospects.



During this financial year there have been three major awareness campaigns; **Darker Pink, Metastatic May “Cost of Living”** and **“Who Really Cares”** for Breast Cancer Awareness Month. In addition, in late December 2024, Jo Taylor was interviewed Radio 5 to mark her New Year Honours BEM. She talked about MBC and METUPUK's campaign priorities.

DARKER PINK

The interactive and powerful experience of the Darker Side of Pink installation continued its journey throughout the UK. The disease continues to be the biggest killer of women in England aged 35-64*. The installation features 31, dark pink life-size Perspex figurines representing the 31 women who die of metastatic breast cancer every day in the UK. Each figurine has a QR code linking to a video of that woman speaking about the issues she faces living with a diagnosis of metastatic breast cancer.



Treadmills, Northallerton Yorkshire

With amazing support from North Yorkshire Council, the installation appeared at the Treadmills for an extended stay of three months. Councillor Michael Harrison, executive member for health and adult services, was delighted to see the exhibition featuring prominently for the North Yorkshire community to visit.

From Northallerton, the installation moved south to Brighton, appearing in the Jubilee Library from December to early January. It gained coverage in the local Argus

“It is sending out vital messages to everyone and we urge people to go along and listen to what these women are saying.”

Councillor Michael Harrison.

In May, the installation appeared at the original site of the oldest prison in the UK which sits in the Richmond (Yorkshire) constituency, home to Laura Ashurst, trustee, and one of the 31 Darker Pink figurines.

Leading causes of death by age group, England, 2020 Source: Office for National Statistics Nomis.

newspaper and was supported by TV actress Elizabeth Carling whose twin sister, Laura Ashurst is one of the 31 women represented within campaign.



Jubilee Library, Brighton

**“Knowledge is power.”
Elizabeth Carling.**



Jubilee Library L-R Vic Revill-Whelan, Elizabeth Carling, Sophie Blake, Laura Ashurst, Kat Southwell, Jessie Lynch and Allison James.

February saw the installation move to the University of Reading, hosted by the School of Psychology and Clinical Language Sciences and Professor Nazanin Derakhshan, a long-term supporter and friend of METUPUK. From Reading the installation moved to Oxford, the home of Kat Southwell, METUPUK patient advocate. It appeared in Oxford Westgate Library for the month of March.

A selection of the Darker Pink figurines also made it to the Cancer Alliances Metastatic Breast Cancer conference, hosted by Greater Manchester Cancer Alliance. Looking forward to 2025 -2026, the touring exhibition will pause for a short period while the materials of the figures are refreshed.



The figures will then kick off new destinations starting with Newcastle.

Volunteers (L) Kirstin Spencer and (R) Kat Southwell at Greater Manchester Cancer Alliance MBC Conference



Westgate Central Library, Oxford

METASTATIC MAY 2024

Since May 2021, Metastatic May has given a dedicated month to spotlight metastatic disease, driving awareness and making clear that MBC patients are worth investing in. Set apart from Breast Cancer Awareness Month in October, it keeps focus sharp and isn't drowned out by pink-washed narratives.

For METUPUK's 2024 Metastatic May, focus centred around the "Cost of Living", set against the backdrop of a year and a half drug campaign for Enhertu for HER2-low

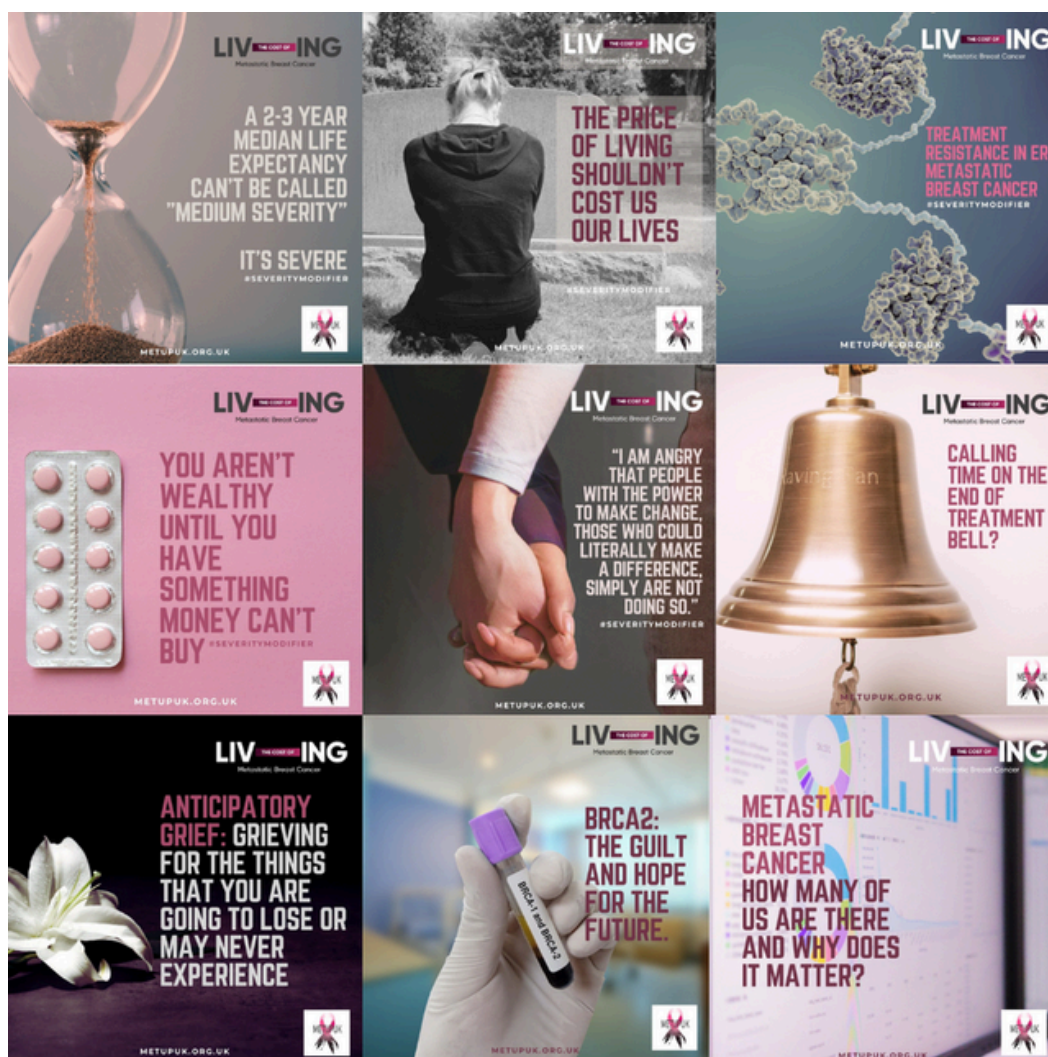
MBC, which resulted in scrutiny on the severity modifier calculation used by NICE.

Metastatic May covered a wide breadth of topics, with volunteers writing both educational and supportive blogs for the wider MBC community. It also showcases the Chrity's many volunteers whose work underpins technical appraisals for NICE and SMC.

"It is illegal to help someone die in this country...isn't denying MBC patients drugs that could add years to their lives the same thing? How can the maze and obstacles of red tape, out of date sequencing, bartering with pharmaceuticals etc not be seen as guiding the patient to an unnecessary early death?"
@lifeislike_that

LIV THE COST OF ING

Metastatic Breast Cancer

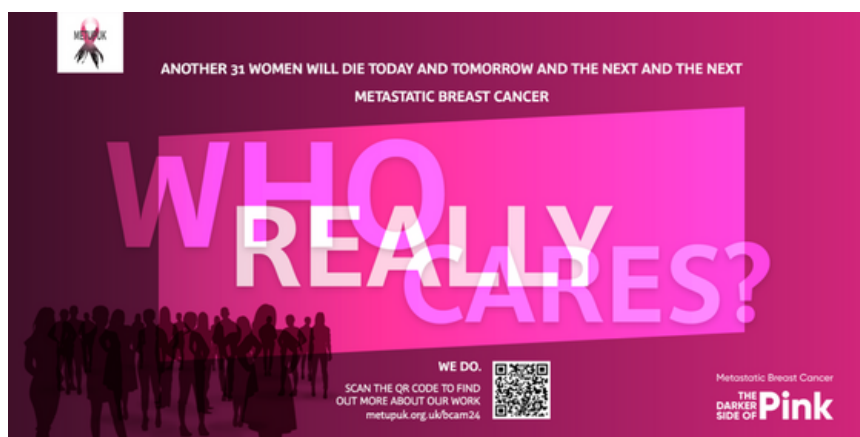


Built to expand which drugs get extra funding, the two-tier severity modifier system with medium and high has fallen short for MBC. Despite its serious nature and shorter life expectancy, all assessed MBC treatments have been placed in the medium tier under the new methods.

WHO REALLY CARES 2024

For Breast Cancer Awareness Month (BCAM) 2024, the Charity's campaign focussed around a call to action on the issues impacting those with MBC and the criticality of issues faced.

Volunteers wrote blog posts highlighting the issues key to them.



Volunteer Helen Crawford wrote about the time stolen by MBC while living with it trying to prolong our lives.

The campaign was successful across all of the Charity's social media platforms, with comments around our stories resonating with other MBC patients. Focus on de novo patients, where diagnosis is stage 4 from the start also attracted a lot of support from readers.

Thank you to the families who were happy for us to re-share stories from those who have sadly died. We appreciate both the heartbreak and pride that campaigns bring to loved ones.

"WHO REALLY CARES" was both a digital and social campaign designed to raise awareness about the devastating impact of MBC. By using a seemingly apathetic question, the campaign aimed to jolt the audience out of complacency and force them to confront the lack of attention this critical issue receives. It serves as a call to action. Implicit in the question is the answer: We should all care!

Around the UK, the campaign was across digital boards in bus shelters and impactful high-traffic roadside locations across the major cities in the UK including London, Bristol, Cardiff, Swansea, Birmingham, Nottingham, Manchester, Liverpool, Leeds, Newcastle, Edinburgh and Glasgow.



Volunteer Helen Thomas wrote about the challenges of getting onto a clinical trial, both in terms of finding suitable trials and the distance required to take part.

RESEARCH AND ACCESS TO DRUGS



METUPUK Aims and Objectives:

- Work with life science companies to increase the number of MBC trials in line with the MBC number of patients, recognising the real potential to extend and save their lives.
- Work to make breast cancer trials more accessible to patients with MBC.
- Submit evidence to the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) to speed up the drug approval process for new drug treatments for MBC.
- Maximise technological advances to improve collation and analysis of data and statistics for MBC.
- Encourage decision makers to use information to better inform treatment decisions.

IMPROVING ACCESS TO DRUGS

Drug access is one of the key objectives of METUPUK because new drugs are needed to increase survival outcomes for patients with MBC. To achieve this we work as stakeholders with NICE and the SMC, who are responsible for ensuring that drugs and medical devices are value for money for the NHS. We bring the patient voice into the drug approvals process. All our written submissions are compiled in collaboration with patients who have the subtype of metastatic breast cancer being reviewed in relation to the proposed drug. We also send patient advocates to speak directly to the committees. The committees are dominated by health economists, scientists and drug companies, and so it is important for these decision-makers to hear from the patients who will benefit from the technology being appraised.

Recommendations made by NICE apply to NHS patients in England and are adopted in Northern Ireland and Wales. Acceptances by the SMC apply in Scotland. On our website we publish treatment line infographics for the three main subtypes of metastatic breast cancer and indicate if there are any differences in NHS access across the UK. Clear information on treatment availability, treatment line restrictions and differences in access across the devolved nations provides a valuable resource for patients to refer to in discussions with their oncologist.

The following drugs for MBC were approved during the financial year 1 April 2024 to 31 March 2025:

- **Elacestrant for Hormone receptor-positive HER2-negative MBC with an ESR1 mutation (NICE)**
- **Olaparib BRCA1/2-positive HER2-negative MBC (NICE and SMC)**

Additionally, Enhertu for HER2-low MBC received the final rejection from NICE in July 2024 after a 21 month long process which culminated in an unsuccessful appeal by Breast Cancer Now and the UK Breast Cancer Group. They appealed on the grounds that the recommendation is unreasonable in the light of the evidence submitted to NICE concerning overall survival extrapolation. We were supportive of the appeal and were very disappointed that it was not successful. With Enhertu for HER2-low available in Scotland and over 20 other countries, this is an example of a divisive postcode lottery.

Only two new drugs were recommended by NICE and one accepted by the SMC in this financial year. The drug appraisals for olaparib were carried out by NICE using a cost comparison approach and by the SMC using a streamlined process. This shortened process was possible because the PARP inhibitor talazoparib, a similar medicine, is already available on the NHS.

ELACESTRANT

The NICE drug appraisal for elacestrant is an example of how patients can provide evidence to a committee which makes real a difference. Elacestrant is recommended by NICE for patients with a mutation in the ESR1 gene who have received at least 12 months of endocrine therapy. It is a selective oestrogen receptor degrader which has been shown in trials to be effective in patients with an ESR1 mutation.

The gene ESR1 encodes part of the oestrogen receptor, and ESR1 mutations change its molecular structure enabling cancer to develop resistance to endocrine therapy. Changes in the ESR1 receptor are unusual in untreated breast cancer but occur in about 30% of hormone receptor positive MBC after treatment with an aromatase inhibitor. Cancer treatments can drive changes in disease, and this is one mechanism in which cancer can evade treatments which initially worked well.

Our patient expert Kirstin Spencer has a scientific background and explained to the committee how there are several different ESR1 mutations. She described how current standard of care at second line is particularly ineffective for patients with certain ESR1 mutations and how elacestrant would fulfil an unmet need. She was complimented afterwards on her confident delivery by independent advocates who viewed the committee.



Kirstin Spencer

The drug elacestrant has also brought ctDNA testing into the breast cancer pathway. ctDNA (circulating tumour DNA) are tiny fragments of genetic material shed into the bloodstream by dying cancer cells. These fragments can be identified in a blood biopsy, a simple blood test for the patient. Scientists can distinguish tumour DNA from normal host DNA by comparing differences in the sequence. This is technically not easy because ctDNA is present at very low levels compared to host DNA, and only a few labs in the UK are able to do this test at volume.

METUPUK patient advocates Jo Taylor and Madeleine Meynell are both involved with their local NHS Genomics Medicines Services, and Jo is also involved with Genomics England. Once elacestrant was recommended by NICE, both worked behind the scenes to emphasise how important it was for ctDNA testing to roll out without delay. We are pleased to report that testing for ESR1 variants has been made available through two Genomic Laboratory Hubs (GLH), North Thames (Royal Marsden Hospital) and the North West (Manchester University Hospital). These labs process all samples in England, and further labs are expected to be announced in the future. Wales and Northern Ireland also have ctDNA testing available for patients via the All Wales Medical Genomics Service and Belfast Clinical Genetics Service.

At METUPUK we have been campaigning for years for the introduction of ctDNA into the metastatic breast cancer pathway. Tissue biopsies are often painful and can only test the cells in the sample. For patients with widespread mets, ctDNA is particularly useful. Different clones of cancer cells can carry different mutations causing them to respond differently to treatment. A blood biopsy can capture ctDNA from all parts of the body enabling scientists to evaluate genomic changes in all cancer cell clones.

Our hope is that as ctDNA technology improves and reduces in cost that it will be rolled out further to other parts of the breast cancer pathway. This is the first step in the right direction.

There is much work still to be done to ensure equitable access to therapeutics within the whole of the UK and between the patients treated in the private sector and the NHS.



Top L-R Madeleine Meynell, Mary Huckle and Kirstin Spencer
Bottom L-R Asha Umrawsingh, Jo Taylor and Helen Stewart.

Access to medicines is a group effort at METUPUK, with many people working tirelessly behind the scenes. Particular thanks to the following patient advocates for their work in NICE and SMC submissions and drug access campaigning; some of these patients are no longer alive but their legacy lives on in their work and their advocacy:

Mary Huckle, Kirstin Spencer and Asha Umrawsingh for work on Enhertu for HER2-low, Kirstin Spencer and Helen Stewart for work on olaparib and Kirstin Spencer, Madeleine Meynell and Jo Taylor for work on elacestrant.

PATIENT TREATMENT AND CARE

CONTINUING THE LEGACY OF CHANGE IN WALES

METUPUK is proudly continuing the legacy of the late Tassia Haines, whose tireless campaigning shaped key priorities for metastatic breast cancer in Wales. In June 2024, Tassia received a Moondance Cancer Award for Patient and Public Participation and Involvement. The award was accepted posthumously by her husband, Nick, alongside the secondary breast cancer community who celebrated her determination to improve equity of care for people with MBC in Wales.



Moondance Cancer Award L-R Ann Baker, Mags Holloway, Nick Brayley, Zoe Barber and Sue Thomas.

KEY ACHIEVEMENTS AND PROGRESS

MBC Pathway Implementation Across Wales

The NHS Wales Executive and individual Health Boards have continued work to implement the Metastatic Breast Cancer Pathway, developed with clinician and patient input, to standardise care and improve outcomes for patients with MBC in Wales. The pathway includes the 'red flag' infographics developed by Jo Taylor's ABCDiagnosis, an invaluable tool to raise awareness of MBC in both primary and secondary care settings and support earlier diagnosis and treatment.



Secondary Breast Cancer Nurse Coverage

Currently, with the exception of one Health Board, Secondary Breast Cancer Clinical Nurse Specialists (SBC CNS) are now in post across Wales, offering invaluable care and support to their patients. However, large patient caseloads have recently highlighted the urgent need for increased nursing capacity to meet demand.

Addressing the MBC Data Gap

METUPUK continues to highlight the lack of robust MBC data in Wales. The NAO Me audit and State of the Nation report have brought this issue to the fore and the

collaborative work with clinicians, Welsh Cancer Network, NAOE, allied charities and patients is continuing to strive for improved data collection. We remain committed to ensuring that meaningful data collection informs service design and accurately reflects the needs of those living with MBC in Wales.

Primary Care Education & Awareness

Recognising the gaps in primary care knowledge around MBC, METUPUK has increased its focus on educational engagement with GPs and primary care clinicians, who should play a vital role in identifying the signs and symptoms of metastatic breast cancer. In January 2025, the Charity took part in its first educational event for primary care at the Cwm Taf Morgannwg University Health Board, Educational Academy, held at the University of South Wales. The awareness stand engaged with over 100 GPs and primary healthcare clinicians, sharing the ABCDiagnosis red flag infographics and raising awareness of the MBC pathway. Several further educational events are planned for the coming year, aiming to expand understanding of MBC presentations in the primary care setting, and encourage timely referral and diagnosis.



Cwm Taf Morgannwg University Health Board, Educational Academy, L-R Sue Thomas and Sarah Brown

Collaborative Approach

The volunteer team in Wales continues to work collaboratively with; The Welsh Government, NHS Wales Executive and Welsh Cancer Network, Welsh Health Boards, Wales Cancer Alliance, Cancer charities and clinical networks. These partnerships are vital to drive forward our shared goals of improved patient outcomes and equity of care across Wales.

Priorities for 2025–2026

- Full implementation of the MBC Pathway across all Welsh Health Boards.
- Further increase in dedicated SBC nurse numbers, ensuring sustainable workloads and quality patient support.
- Continued advocacy for national data collection through NaoME and wider cancer data strategies.
- Ongoing roll-out of primary care educational initiatives, targeting GPs, nurse practitioners, and allied healthcare professionals.
- Launch of “Tass’ Legacy” project, funded from a restricted donation (see page 25).

NORTHERN IRELAND

METUPUK membership of Northern Ireland Cancer Charities Coalition (NICCC)

METUPUK joined the Northern Ireland Coalition (NICCC) in early 2024 and showcased its work at the official launch at Stormont Parliament Buildings in June 2024.

Throughout the year, Ann McBrien, METUPUK's Northern Ireland representative, has worked collaboratively with NICCC partner charities to address issues and improve outcomes for cancer patients. This work has included publicly highlighting poor cancer waiting times and the impacts of the Department of Health's 2024/25 draft budget assessment and projected cost saving measures.

Breast Services Review

Ann McBrien has increased awareness of metastatic breast cancer and pushed for the implementation of the recommendations relating to it in the Northern Ireland Cancer Strategy 2022-2032. METUPUK has had a strong voice at the Regional Breast Services Review established by the Health Minister in 2024, ensuring that stage 4 cancer patients are not overlooked in the improvement plans.



Northern Ireland Cancer Charities Coalition (NICCC)

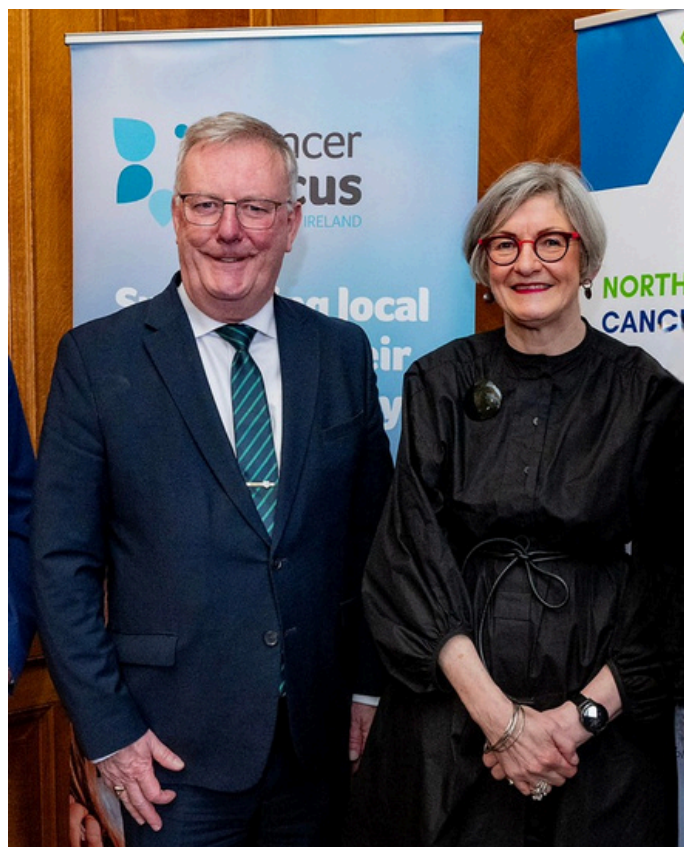


Northern Ireland Cancer Charities Coalition (NICCC)

Metastatic Breast Cancer Data

METUPUK has campaigned tirelessly for over a decade for improvements in cancer statistics and the inclusion of cancer recurrences in metastatic breast cancer data across the UK.

In 2024, Ann McBrien was part of a groundbreaking research study which produced statistics on new and existing cases of metastatic breast cancer in Northern Ireland. Publication of this research, which was carried out by the Northern Ireland Cancer Registry, placed Northern Ireland amongst one of the first countries in the world to count all metastatic breast cancer patients. The research, funded by Cancer Focus Northern Ireland, linked population based cancer registry data with hospital data and detailed death record information. It estimated that approximately 1,000 people are living with the disease in Northern Ireland, with around 250 new cases diagnosed annually.



L-R Mike Nesbitt, Northern Ireland Health Minister, Ann McBrien



Ann McBrien at launch of MBC Data Research

Ann who was a coauthor of this research, along with the Director and staff from the Northern Ireland Cancer Registry, presented the findings to the Minister at Stormont Parliament Buildings. The Health Minister has committed to the development of a metastatic breast cancer pathway as part of the Regional Breast Review.

SUPPORT FOR FRIENDS AND FAMILY



Whilst METUPUK does not offer direct support services for patients with metastatic breast cancer, we actively signpost individuals to trusted groups run by other registered charities. Our focus is on complementing existing services rather than duplicating them.

Recognising the limited support available for friends and family of those affected by MBC, METUPUK has been running a confidential Facebook support group since 2021. This group is moderated by Emma Smith, a METUPUK Trustee with personal experience through her sister Helen, who lives with MBC.

The group offers a safe and compassionate space for peer support. Members are encouraged to share their thoughts, emotions, memories and experience, whatever they feel comfortable expressing. Whether someone is supporting a loved one undergoing treatment, providing end-of-life care, or grieving someone who has passed, the group fosters connection and understanding.

Key moments, such as Christmas and New Year, can be especially challenging. During these times, members are invited to share stories and memories of their loved ones, offering comfort and solidarity to others who may be struggling to find support outside of the group.

This community helps ensure that no one feels alone, whatever stage they are at in supporting someone with MBC.

In order to help keep conversations frequent and provide a positive outlet for support, the group also shares fundraising efforts for METUPUK. The amazing achievements from our fundraising community are shared on pages 22 and 23.



FUNDRAISING AND DONATIONS



METUPUK is funded almost entirely by fundraising and donations (see page 24). The Charity is incredibly grateful to all the donors who have supported our work this year and the time taken to undertake challenges and events in our honour. The Charity has a dedicated fundraising Trustee, Emma Smith, to help provide support, merchandise requests and promote events on social media.

Paul Green, a member of the local Cotswolds band “Wolds”, wrote “Sarah’s Song” for his friend Sarah Brown. Released on 12 August 2024, all monies from streaming and song purchases are donated to METUPUK.

Ever-popular running challenges made a significant difference for the Charity this year with volunteer and MBC patient Helen Crawford running the Great North Run, alongside her sister Emma (our Fundraising Trustee) and their younger brother Kenny.



In October 2024, Zoe Barber, a consultant breast surgeon based in Wales, ran the Cardiff Half Marathon and also achieved a Guinness World Record for the “fastest runner dressed as a cartoon character (female)”.

Callum Day, a family friend of METUPUK’s Founder Jo Taylor, did a skydive on 14 September 2024.

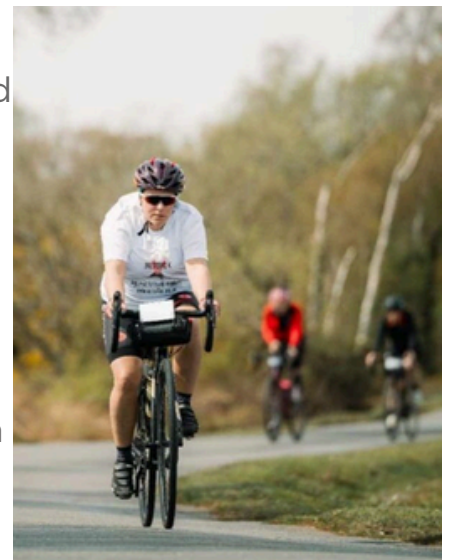


In March 2025, METUPUK were pleased to be invited by Elle Egar from the TV show “The Real Housewives of Cheshire”, to participate in the filming of an episode. Elle’s mum, Lisa, is living with metastatic breast cancer and Elle organised “Ell’s Par-Tea for a Good Cause”, to raise awareness of MBC and to raise funds for METUPUK and The Pink Ribbon Foundation. Laura Ashurst, METUPUK Trustee, was invited to the event and spoke to the attendees about METUPUK and living with MBC. Huge thanks to Elle for the invitation and to all the cast and crew from the show. The TV episode was broadcast in May 2025.



IN MEMORY

Donors also continue to raise funds in support of trustees and volunteers of METUPUK, as well as their own friends and family, who have been diagnosed with, or have died from MBC. Lauren and Marianne, friends of Connie Johncock (who was a founding trustee of METUPUK), cycled the New Forest Sportive 92km Cycle Route in April 2024, in Connie’s memory.



Louise Kettle and friends took part in the Derby 5k Mud Run in June 2024, in memory of their old school friend Philippa Hetherington.

Sara Percy completed the Saddleworth Three Peaks in July 2024, in memory of her, and our Founder Jo Taylor’s, friend Sara Giddens.

Hilary Turnbull hosted “Laura’s Do” (an evening of music, food, raffles and celebration) in January 2025 in memory of her daughter Laura.



In March 2025, Emily Laverick, daughter of Rebecca Laverick, ran the Rome Marathon.



OUR FINANCES

Financial Review

The Charity was registered on 9th November 2021 and has now completed a third financial year (running from 1st April 2024 to 31st March 2025). The Charity's income for this period exceeded expenditure by £21k, leaving the Charity in a stable position at the end of the financial year.

Expenditure summary 2024-2025

The Charity's funds have been used effectively and have been spent in line with our objectives. The largest item of expenditure continues to be for attendance at events to further awareness of, and to provide education about, MBC and also to fund our annual campaigns for Metastatic May and, in October, for Breast Cancer Awareness Month (BCAM).

Income summary 2024 - 2025

For the financial period, the Charity's main source of income was donations, comprising 60% of the total funding. The remaining income was generated through a number of Charity-led fundraising activities and restricted grant funding from Nick Brayley on behalf of his wife Tassia Haines. (see page 18 for more details).

STATEMENT OF FINANCIAL ACTIVITIES

N4

Client:	METUPUK	Prepared By:	DH
Year Ended:	31 March 2025	Date:	20/10/2025
		Reviewed By:	
		Date:	

RECEIPTS AND PAYMENTS ACCOUNTS

	Unrestricted	Restricted	2025	2024
Receipts				
Fundraising	17,306.44	-	17,306.44	3,082.59
Donations	33,635.67	-	33,635.67	50,760.96
Grant income	-	6,278.44	6,278.44	20,000.00
Other income	-	-	-	3,809.20
Investment income	982.12	-	982.12	58.27
	<u>51,924.23</u>	<u>6,278.44</u>	<u>58,202.67</u>	<u>77,711.02</u>
Payments				
MBC awareness / Education events	29,141.65	-	29,141.65	54,076.39
Education/ Communications	750.00	-	750.00	327.44
Other costs	4,520.95	-	4,520.95	2,409.19
	<u>34,412.60</u>	<u>-</u>	<u>34,412.60</u>	<u>56,813.02</u>
<u>Governance costs</u>				
IT/ Website/ SM/ Telecoms	145.20	-	145.20	1,027.80
Insurance	156.49	-	156.49	171.55
Legal and governance costs	1,506.00	-	1,506.00	3,000.00
	<u>1,807.69</u>	<u>-</u>	<u>1,807.69</u>	<u>4,199.35</u>
Receipts less payments	15,703.94	6,278.44	21,982.38	16,698.65
Funds transfer	4,856.43	- 4,856.43	-	-
Total funds				
Balance brought forward	73,994.39	4,856.43	78,850.82	62,152.17
Balance carried forward	<u>94,554.76</u>	<u>6,278.44</u>	<u>100,833.20</u>	<u>78,850.82</u>

STATEMENT OF ASSETS AND LIABILITIES

	Details	Unrestricted	Restricted	2025	2024
Cash funds	Lloyds bank	94,554.76	6,278.44	100,833.20	78,850.82
Liabilities	Independent Examiner's fee	960.00	-	960.00	900.00

Signed by one of the trustees on behalf of all the trustees

Signature	Print name	Date
	Philip Southwell	30/11/2025

Reserves Policy

METUPUK holds a minimum of 12 months running costs in reserve from unrestricted funds. These running costs include IT/telephone costs including Microsoft accounts, website hosting and support, virtual assistant fees and the cost of running ongoing campaigns such as the Darker Pink exhibition. We also need to set aside provision for professional fees such as accountancy and legal advice should the charity be closed. The funding of METUPUK relies mainly on donations via funding platforms, which varies between month to month. Any funding via grants are generally restricted funds which cannot form part of the reserves policy. The running costs vary according the number of active volunteers who require IT access and the cost of campaigns. The reserve set for this year is £25,000, and this figure will be reviewed by the Trustees on an annual basis.

ADMINISTRATION

List of Trustees as at 30 November 2025

Emma Smith – Fundraising (appointed July 2023)

Dr Helen Steele – Research and Clinical Trials (Founding Trustee)

Laura Ashurst – Darker Side of Pink (appointed March 2025)

Phil Southwell – Finance and Technology (appointed November 2023)

Sue Thomas – Wales Executive Lead (appointed October 2025)

Madeleine Meynell stepped down in November 2024

Andy Figgins stepped down in December 2024

Nicky Goldthorpe stepped down in October 2025

Jo Taylor (Founder/Chair) died on 3 November 2025

The Charity's Registered Office is:

4 West End Barns, West End, Northwold, Thetford, Norfolk IP26 5NE

The Charity's Independent Examiners are:

KM Chartered Accountants, 1st Floor, Block C, The Wharf, Manchester Road, Burnley BB11 1JG

The Charity's bankers are:

Lloyds Bank plc, 25 Gresham Street, London EC2V 7HN

Risk Management

METUPUK is committed to ensuring practices which will ensure consistent risk management approaches are in place across the organisation. Managing risk is seen as a key organisational responsibility and is integral to the management and governance of the Charity. We recognise that effective risk management is achieved by ensuring that Trustees and the whole volunteer team is engaged with managing and mitigating risk.

We are proactive in identifying all potential risks and in analysing and managing risks. During the year, a risk register was developed and is now being reviewed by Trustees on a regular basis. We will ensure good communications across the organisation to support learning and increasing good practice. We recognise that it is not possible to eliminate risk but aim to manage, mitigate and minimise risks across the Charity wherever possible.

INDEPENDENT EXAMINERS REPORT

Independent Examiner's Report to the trustees of METUPUK

I report to the trustees on my examination of the accounts of METUPUK for the year ended 31 March 2025.

Responsibilities and basis of report

As the Trustees of the Charity, you are responsible for the preparation of the financial statements in accordance with the requirements of the Section 145 of the Charities Act 2011 ('the 2011 Act'), the Charities and Trustee Investment (Scotland) Act 2005 ('the 2005 Act') and the Charities Accounts (Scotland) Regulations 2006 (as amended) ('the 2006 Accounts Regulations').

I report in respect of my examination of the METUPUK financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all the applicable directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement



I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act and Regulation 4 of the 2006 Accounts Regulations; or
2. the financial statements do not accord with those records; or
3. the financial statements do not comply with the accounting requirements of the Charities (Accounts and Reports) Regulations 2008 or Regulation 8 of the Accounts Regulations 2006 other than any requirement that the financial statements give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

M R Heaton FCCA FCIE DChA
KM Chartered Accountants
1st Floor, Block C
The Wharf
Manchester Road
Burnley
Lancashire BB11 1JG

Date: 27 November 2025

It's not fun knowing that
we feel invisible and that
no one is listening to us.

Jo Taylor

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
so many of us are unaware
of the red flags symptoms.

Mary Huckle

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
it's a struggle to access any
ongoing NHS mental support.

Laura Ashurst

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
there doesn't seem to be a test
to show who is or potentially
who isn't going to be cured.

Kirstin Spencer

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
I'm planning my funeral. It's not
something that someone at 39
years old should be doing.

Carole Pollard

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
I'm less likely to access
clinical trials because
I take other medication.

Madeline Meynell

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
I had to self fund treatments
as there was nothing
else approved on the NHS
available to me.

Phillipa Hetherington

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that
we don't even have clinical
trials based on black
women's experiences.

Leila Asoko

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**

