

METUPOK ANNUAL REPORT

6 APRIL 2023-31 MARCH 2024



Second Annual Report (6 April 2023 – 31 March 2024)

METUPOK (Metastatic Exchange to Unleash Power UK)

METUPOK 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

METUPOK 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 11 Lower Knoll Road, Diggle, Oldham OL3 5PD
email: contact@metupuk.org.uk

“I’m passionate about creating change for patients especially those with MBC. The only way change will happen is for us to demand change together as a community. We cannot continue with the same outcomes and with women dying at the same rate.”

Jo Taylor, METUPUK Founder and Chair



Jo Taylor hosting the first UK patient led Metastatic Breast Cancer conference, June 2023 (page 12)

Another 12 months have passed as a registered charity and we have gone on to achieve so much in a short space of time. As we ended our first year as a Charity, we were at the Houses of Parliament with the Darker Pink exhibition, and quickly went into June 2023 where we hosted the first dedicated patient-led Metastatic Breast Cancer conference in the UK. To see our strategy for the last seven years coming to fruition has driven us further; always with those no longer with us at the front of our minds.

Awareness is a huge issue for Metastatic Breast Cancer (MBC) and seeing the Charity getting the message out to the devolved nations this year has been incredible. England’s Cancer Alliances are looking at using the End of Treatment Summary reports developed in Greater Manchester in conjunction with the infographics. In Wales, the infographics are being embedded as part of the NHS pathway. In Scotland they are now part of the Cancer Strategy and its website for patients and clinicians. There is still much work to be done, but the foundations are finally coming together. This has taken over 10 years to get England alone to have this focus on MBC, the hidden disease. For Northern Ireland, MBC patients have been left behind for many years without a cancer strategy. We welcome the publication of the Cancer Strategy for Northern Ireland 2022-23 and urge the Minister to ensure it is fully funded and implementation progresses in line with plans. We were also delighted in March to apply as a full member of the Northern Ireland Cancer Charities Coalition (NICCC), a partnership of organisations with a shared vision across the cancer landscape in Northern Ireland. (The application was accepted in April 2024, outside of the reporting period of this Annual Report).

Our board has gained two new Trustees; Phil Southwell, responsible for finance and

technology and Emma Smith, responsible for fundraising. We are incredibly grateful to all our generous fundraisers who enable us to keep driving change forward. Read all about fun and the painful (!) fundraising on page 21.

The year continued to see a number of volunteers die from metastatic breast cancer. Their voices, their bright souls and their drive for better will continue to shape and influence us as we mourn the loss of them.



MARY HUCKLE

Volunteer
Died June 2023



KIT DZERYN MBE

Volunteer
Died May 2023



ASHA UMRAWSINGH

Volunteer
Died March 2024



EMMA SAVILLE

Volunteer
Died July 2023



TASSIA HAINES

METUPOK Lead for Wales
Died March 2024

At the end of our 2023-24 financial year, our net profit was £16,699. We rely on the work of our Trustees and also our patient advocate volunteers. None of us draw a salary from the Charity and METUPOK 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 METUPOK

“A 2-3 year median life expectancy for Metastatic Breast Cancer is not a statistic to rejoice in but rather a demonstration of how much more needs to be done.”

OUR PEOPLE



Trustees during financial period April 2023- March 2024 were Jo Taylor (Chair), Andy Figgins, Emma Smith, Helen Steele, Julia Bradford (resigned December 2023), Madeleine Meynell and Phil Southwell. Current Trustees are listed on page 25.

Founding Trustees were recruited from volunteers of the METUPUK precursor organisation and worked together to create the Charity. 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



ANDY FIGGINS
Trustee - Friends and
Family Support



EMMA SMITH
Trustee -
Fundraising



DR HELEN STEELE
Trustee - Volunteers and
People



MADELEINE MEYNELL
Trustee -
Access to Drugs



PHIL SOUTHWELL
Trustee -
Finance and Technology

VOLUNTEERS

In addition to the METUPUK Trustees, all charitable activities rely on the hard work and dedication of a team of volunteers. As of 31 March 2024, 33 active volunteers from across all regions of the UK were working with METUPUK. The volunteers are at the heart of everything that METUPUK achieves. All volunteers have been personally affected by metastatic breast cancer. The majority are MBC patients, while others are friends and family of MBC patients or have lost a loved one to the disease. The Charity's MBC patient advocates are vital as they bring a voice to the statistics, for example by sharing their stories in campaigns and providing patient input to the drugs approvals process. One of the hardest things for all involved in METUPUK is that volunteers frequently die from MBC, reflecting the harsh reality of this disease. This year METUPUK mourned the loss of Kit Dzeryn, Mary Huckle, Asha Umrawsingh, Emma Saville and Tassia Haines.

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 website

maintenance, campaigns and producing the monthly newsletter. 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 access to Sharepoint and funding patient advocates to represent METUPUK at meetings and events. See page 24 for 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

METUPOK 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** and **Disappearing Lives**. In addition, in April 2023, Jo Taylor was a guest on BBC Radio 4 Woman's Hour speaking about MBC, her story, the infographics she created and promotes for use in the NHS and the work of METUPOK.



DARKER PINK

The Darker Side of Pink' physical interactive experience continued touring the UK this year with a number of new locations, highlighting the seriousness of MBC; the biggest killer of women in England aged 35-64.*

The impactful exhibition features 31 life-size transparent figures, depicting the invisibility of the disease – each one representing a woman who dies every day in the UK. METUPUK Trustee Connie Johncock, who died in March 2023, helped to organise Darker Side of Pink to exhibit at Rochester Cathedral. Connie had lived nearby and her family and friends came together with Cathedral staff and local MP to launch the exhibit in May 2023.



The figures were arranged throughout the cathedral to show how MBC patients walk among us. Connie's vision for within the building was for a figure to be visible from every aspect that the public might be in the building.

The launch event brought mixed feelings for all who attended as Connie died before seeing her plan come to reality. Her death also amplified the importance of METUPUK's work.

'The Darker Pink' figures feature a QR code that, when scanned, plays a video from a real-life woman living with MBC. Filmed in 2021, many of these women have since died (including Connie), themselves becoming a

“It is a poignant honour for us at Rochester Cathedral to welcome the installation of the Darker Side of Pink silhouettes.....it is very important that we align ourselves with all those who are campaigning for better treatment and care for those who suffer from breast cancer and we are delighted to be able to do that.”

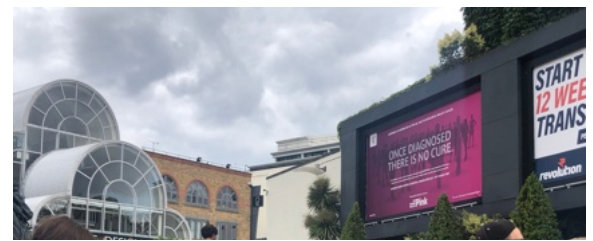
The Rev'd Canon Dr Gordon Giles,
Canon Chancellor at Rochester
Cathedral



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

statistic they spoke about whilst also campaigning for change.

The Business Design Centre in London had an extended stay of the exhibition due to its popularity of the campaign. METUPUK was incredibly grateful to the organisation who ensured that the campaign was promoted on a billboard and on escalator digital screens within the building at no cost to the Charity.



Darker Pink made it to Wales, as part of the Welsh MBC Conference in October (see page 18), and is also featured on the cover of the Annual Report.

Looking forward to 2024-2025, the Charity is planning venues in Northern Ireland as well as returning to Scotland for further locations.

METASTATIC MAY 2023

Metastatic May has been running since May 2021, providing a dedicated month to talk about metastatic disease, raise awareness and show that MBC patients are worth investment in. At the opposite end of the year to Breast Cancer Awareness Month in October, it gives more focus for the campaign without being drowned out by the pink washing of positivity that exists across UK media during October.

Each week in May focusses on a different theme; Treatment Lines and Drug Access, Mental Health, Living with Mets and Patient Stories.

Volunteers and supporters of METUPUK write blogs about MBC topics that are both educational and supportive for the wider MBC community finding 'someone like me', whether that be the same worries, challenges or positive action. It also showcases the breadth of volunteers involved in the Charity that underpin work for technical appraisals for NICE and SMC.



August 2023 saw the UK turn pink with the launch of the Barbie film. Given links to breast cancer, the Charity launched a mini campaign highlighting some of the key messages from the perspective of living with MBC. The reaction from the MBC community was incredible, striking a nerve with the anticipatory grief many patients have.

"I don't even know where to start with it all, the persistent enormous grief of lost dreams, a future, plans unfulfilled. Feeling too unwell to even do basic things, feeling like I'm wasting valuable time just resting. Utter sadness at missing out on so many milestones then realising I won't be here to notice that, then feeling selfish..it's overwhelming"

The images reinforced the message **It's not fun living on The Darker Side of Pink.**



DISAPPEARING LIVES 2023

In Breast Cancer Awareness Month (BCAM) 2023, the campaign focussed on the stories of the nine women who had already died since taking part in the Darker Pink campaign. Their stories were re-told of treatment, missed diagnoses, inaccessible treatment lines and failed access to trials.

Each day featured a different story of their 'disappearing lives', alongside providing educational resources.



Top, L-R Anne Cargill, Emily Roberts, Philippa Hetherington
Middle, L-R Emma Saville, Leila Asoko, Mary Huckle
Bottom, L-R Sally Nyland, Connie Johncock, Nina Masoud

The campaign was combined with dissemination of the ABCD Red Flag Infographics for ductal and lobular breast cancer. These infographics highlight the signs and symptoms of metastatic breast cancer and are signposted by NHS England to educate patients and the public.

The Disappearing Lives campaign across all socials was incredibly successful for the charity with over 10,000 plays of one of the stories. This gives a strong educational platform for increasing knowledge and awareness as well as gaining more supporters and volunteers to help with the Charity's aims and objectives.

The Charity would like to thank all of the families and friends of the nine women who appeared in Disappearing Lives. We appreciate both the heartbreak and pride that campaigns bring to loved ones.



CONFERENCES AND EVENTS

In May 2023, the annual **Association of Breast Surgeons** conference was held in Belfast. Our Executive Lead for Northern Ireland, Ann McBrien, was incredibly busy on the METUPUK stand discussing with clinicians the red flag signs and symptoms infographics for MBC. There was great interest in the infographics, particularly amongst nursing staff who play a lead role in educating early/primary breast cancer patients at the end of treatment.

METUPUK was commended for the accessibility of the infographics with clear illustrations, simple language and translations into different languages. Many delegates committed to review the infographics with a view to introducing them within their care pathways.

Ann was also able to raise awareness of her work on the Metastatic/Secondary Breast Cancer Clinical Audit for NI, funded by the charity Cancer Focus NI.

MBC clinical trials in NI were also discussed given the scarce number of MBC trials compared to other parts of the UK.



Ann McBrien, METUPUK Executive Lead for Northern Ireland. ABS conference 2023

MBC CONFERENCE - MANCHESTER JUNE 2023

The first patient-led event of its kind in MBC, the conference brought together members of the MBC multi-disciplinary-team including clinicians, nurses, scientists, researchers and managers for one day to focus on improving regional and national MBC services. The objective was to highlight a 'Case for Change' that could be shared with Cancer Alliances and health systems across England and the rest of the UK. Each speaker was asked to identify calls to action, including any smaller 'quick wins', to feed into follow up actions after the conference.

Speakers covered all aspects of the MBC pathway and were joined by Andy Burnham, Mayor of Greater Manchester for the keynote speech.

METUPUK were incredibly proud to host such a key event and to be the only organisation to do this, driven by the patient voice, in the UK.

The follow up actions to the Conference are available here on the [METUPUK website](#).



Andy Burnham,
Mayor of Greater Manchester



Attendees and Speakers at the MBC
Conference



Jo Taylor, METUPUK. Nazanin Derakhshan,
Building Resilience in Breast Cancer
(BRiC)

UK INTERDISCIPLINARY BREAST CANCER SYMPOSIUM

METUPUK attended the UKIBCS in January 2024. It is hosted every two years by Breast Cancer Now, bringing the world of clinical research, oncology, surgery, radiology, pharma, charities and patients together with the latest news on primary and metastatic breast cancer. The two day event had a packed agenda, with many interesting talks about the latest developments across different types of breast cancer and future treatment options.

The METUPUK stand was busy, with visits from a broad range of delegates, many talking about the Ductal and Lobular MBC infographics. Volunteers shared information on awareness, the work underway with Greater Manchester Cancer Alliance and the clinical trial database on the METUPUK website of MBC trials recruiting across the UK.



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 written 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 6 April 2023 to 31 March 2024:

- **Enhertu second line HER2-positive (NICE and SMC)**
- **Enhertu HER2-low (SMC accepted, NICE provisional rejection)**
- **Talazoparib BRCA 1/2 (NICE and SMC)**

Only three new drugs were appraised in this financial year. There were fewer technology appraisals than in previous years for MBC from both NICE and the SMC.

NICE METHODS AND PROCESSES REVIEW

In February 2022, a review of the NICE Manual of Methods and Processes led to significant changes, particularly regarding funding for drugs treating conditions with short life expectancies. The former "End of Life Criteria," which allowed £50,000 per QALY gained for life-extending treatments, was challenged by NICE, citing that evidence for societal preference was lacking. Consequently, this criteria was replaced by a severity modifier that assesses health loss from severe diseases. The new framework includes a standard willingness to pay (up to £20,000-£30,000 per QALY gained) alongside two severity modifiers: medium (1.2 multiplier) and severe (1.7 multiplier and equivalent in value to the End of Life criteria). The severity modifier has been implemented as opportunity cost neutral, equivalent to the total NHS "End of life criteria" budget.

During METUPUK's first financial year (9 November 2022- 5 April 2023) all NICE drug appraisals were conducted using the previous methods. Many metastatic breast cancer drugs benefitted from the end of life criteria, and NICE and drug companies came to commercial agreements to bring new medications into the NHS in England.

INEQUALITIES IN DRUG ACCESS ACROSS NICE AND THE SMC

All three metastatic breast cancer drugs appraised during the 2023-24 financial year by NICE were given a 1.2 medium severity. A commercial agreement for Enhertu for HER2-low MBC could not be reached, and this drug has not been recommended by NICE, but is accepted by the SMC and available to patients in Scotland.

Enhertu for HER2-low almost certainly would have fallen under the end of life criteria, and is a first in-class drug. No other drugs used in the NHS in England target HER2-low MBC. In Scotland, the SMC retains dedicated methods and additional funding for end of life conditions. Companies can request a PACE (Patient and Clinical Engagement) meeting to describe the added benefits which may not be fully captured during a conventional clinical and economic assessment.

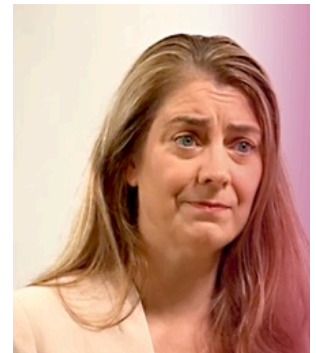
The Enhertu postcode lottery is not unique in the NHS. Last year the drug combination Piqray plus fulvestrant was recommended by NICE for use in England, but not accepted by the SMC. These discrepancies show that unequal access to cancer drugs remains within the UK. There is much work still to be done to ensure equitable access to therapeutics within the whole of the UK and between the patients treated in the private sector and the NHS.

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. Many of these women have since died but their legacy in improving access to medicines lives on:

Emma Fisher for work on Enhertu for HER2-positive MBC at the second line.



Mary Huckle, Kirstin Spencer and Asha Umrawsingh for work on Enhertu for HER2-low.



Kirstin Spencer and Helen Stewart for work on Talazoparib.



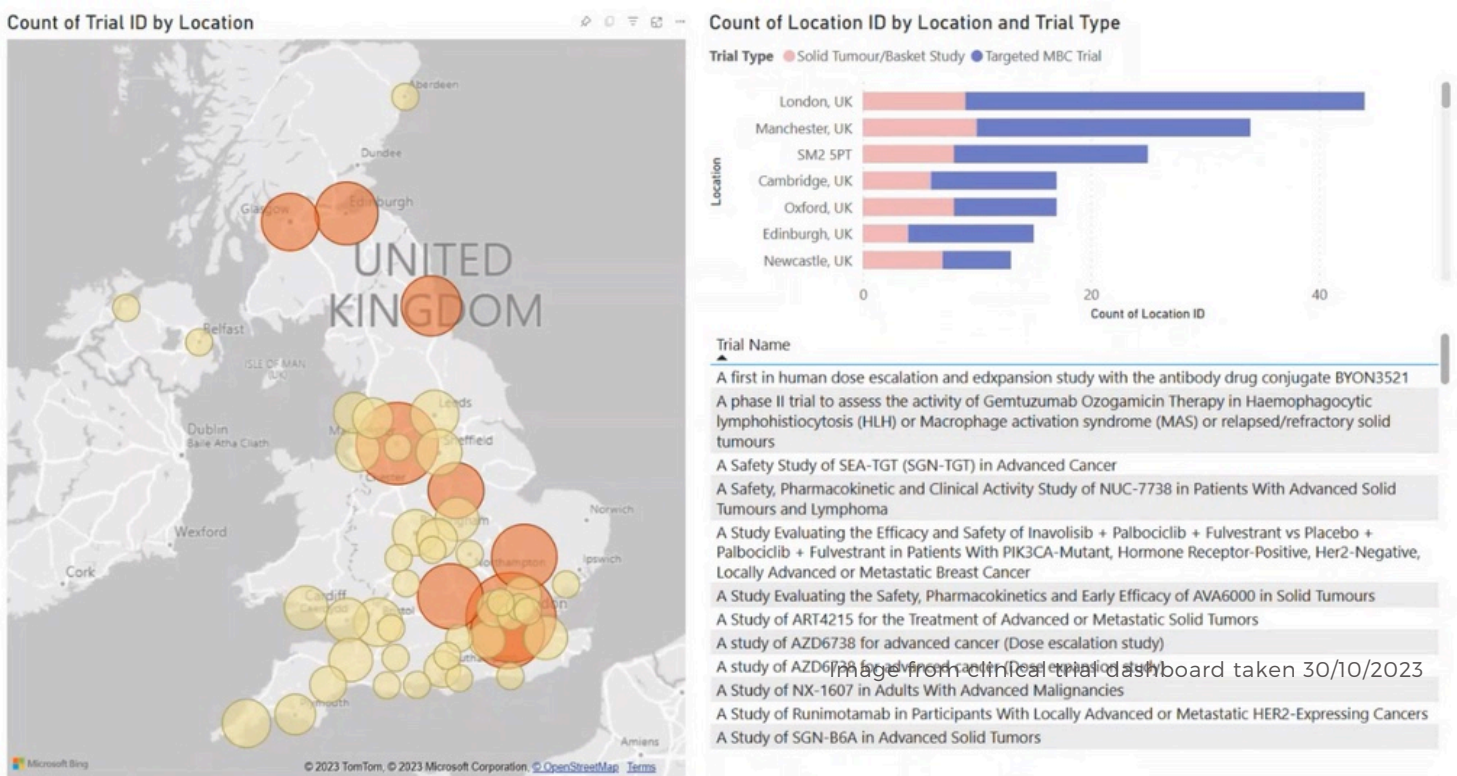
Patricia Snow for her campaigning on access to Piqray in Scotland.

Top L-R Emma Fisher, Mary Huckle and Kirstin Spencer
Bottom L-R Asha Umrawsingh, Helen Stewart and Patricia Snow

CLINICAL TRIALS

METUPUK's work on facilitating access to clinical trials builds on the initiative started by METUPUK patient advocate Beth Roberts in 2018. She constructed a clinical trials spreadsheet to help patients searching for MBC trials. She recognised that the large clinical trial databases were not fit for purpose, and the large organisations that should have been keeping them up to date were not. Trials were missing, trials that had stopped recruiting were being advertised as still open, trials available for MBC patients were not tagged so did not appear in the correct searches. Beth died in 2020, but her work lives on in published form accessible to all on the METUPUK website by a team of two volunteers.

Sadly the challenges of accessing up to date, accurate trial information for MBC still persists, with METUPUK campaigning for patient aimed information such as Be Part of Research to be urgently corrected.



METUPUK's listing as developed further in the financial year, now with dashboards by country and by sub type of disease. The Charity also continues its work with other third sector MBC organisations such as Make 2nds Count to produce the most up to date information for patients to use, wherever they live in the UK.

PATIENT TREATMENT AND CARE

OUR WORK AROUND THE UK - WALES

The Executive Lead for Wales, Tassia (Tass) Haines, had been a significant campaigner for MBC patients since her own diagnosis at 28 years old. Sadly in March 2024, Tassia died of MBC. Her work leaves a huge legacy for METUPUK to continue in Wales, something which she was still driving forward in her final few weeks alive. Tass's passion for change was driven by her own experience of healthcare inequalities. She was not told by any clinicians that there was a risk of developing metastatic disease after her initial primary breast cancer diagnosis. She was turned away from her GP ten times, despite having red flag symptoms. Subsequently she collapsed with spine metastases by the side of the road while out one day and upon hospitalisation, bone mets were found in her legs, hips, spine, ribs, skull and neck. Tass was driven by the stories of other women, who were similarly let down.

The year leading up to her death, saw Tass in May 2023 attending the Petition Committee of Senedd to update on progress that had been made for clinical nurse specialist (CNS) recruitment across Health Board's and for traction in implementing the red flag signs and symptoms of MBC along with a targeted MBC Pathway. From the Committee, Tass took the campaign to the Welsh Health Minister Eluned Morgan and to the National Cancer Clinical Director for Wales, Professor Tom Crosby. Throughout the year, Tass worked with Zoe Barber, Director for Breast Services at Cwm Taf Morgannwg University Health Board and Jo Taylor from METUPUK and After Breast Cancer Diagnosis (ABCD) to roll out the red flag infographics into the pathway for primary patients in Wales. This, coupled with a documented MBC pathway by Zoe Barber, has become Tass's legacy.

This legacy will benefit primary and metastatic patients across Wales for years to come.

In October 2023, METUPUK hosted the first patient-led MBC conference in Wales, to highlight the work in Wales, hear the latest updates on red flag implementation

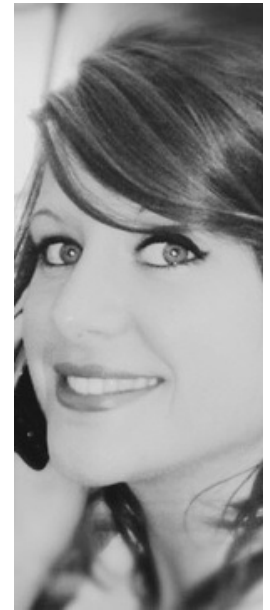


October 2023, METUPUK Conference in Wales.

and the serious situation around lacking clinical data for MBC patients. It was also the first opportunity to present awards created by METUPUK to honour former volunteers.

Carolyn Gammon Award for Outstanding Contribution to Advocacy in Metastatic Breast Cancer

Carolyn Gammon's family joined the conference attendees to honour Carolyn, who was a member of METUPUK in Wales and who died in 2020 from MBC. Tassia Haines received the award in recognition of her campaigning work with Senedd.



Philippa Hetherington Award for Outstanding Contribution to MBC (Clinical)

In remembrance of Philippa Hetherington who spearheaded the campaign for access to Trodelvy and died of MBC November 2022. The award was presented to Zoe Barber, Breast Surgeon.



Connie Johncock Outstanding Contribution to the MBC Community

In remembrance of Connie Johncock, former Trustee of METUPUK, who died March 2023. David Rees MS, who had supported Tass's work with Senedd received the award.

L-R Top: Carolyn Gammon, Philippa Hetherington, Connie Johncock
L-R Bottom: Tassia Haines, Zoe Barber, David Rees MS

The Metastatic Breast Cancer Pathway in Wales was signed off by the Welsh Cancer Network in November 2023, ready for the pathway to be implemented within individual health boards.

Tass was 32 when she died, achieving so much while she was alive to address matters that impacted her and also impacted other patients with MBC. Her legacy of work continues in Wales.

SUPPORT FOR FRIENDS AND FAMILY



METUPUK doesn't provide a support service for MBC patients directly as we do not wish to replicate what is already provided by other organisations. We do signpost patients to groups run by other registered charities. For friends and family, there is less support available. METUPUK have been successfully running a Facebook confidential group since 2021. It is moderated by Andy Figgins, Trustee, whose wife Elaine died of MBC. Emma Smith, Trustee, is also a moderator for the group and has lived experience through her sister Helen who has MBC.

The group provides peer support in a safe environment. Members share thoughts, feelings, memories or anything else which they have on their minds. It provides a safe space for those who wish to open up and share, as well as the wider benefit of members knowing that they are not alone, at whatever point they are supporting someone with MBC. The members are a mixture of those supporting someone under treatment for MBC, supporting end of life care and loved ones of those who have already died of MBC.

Key dates such as Christmas and New Year can be particularly difficult for members and so is one of the main points in the year where the group is encouraged to share stories of loved ones. This brings much comfort to members who can sometimes struggle to find understanding outside of the group.

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 page 21.



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 also welcomed a dedicated fundraising Trustee, Emma Smith, to help provide support, merchandise requests and promote on social media until the event has taken place.

Terry Christian, supporter of METUPUK and our work locally in Manchester, chose us as his nominated Charity when he appeared on Celebrity Mastermind. We are thankful of his ongoing support and generous donation when he won!



Terry Christian



Music Secreta

In February 2024, Musica Secreta supported METUPUK on World Cancer Day by creating a playlist with donations to the Charity. The final fundraising piece of music was aired on Radio 3. It was a motet for St Agatha who is the patron saint of breast cancer patients.

METUPUK volunteer Laura Ashurst tracked her future son-in-law Bren Craggs through a collection of amazing challenges this year, raising money for METUPUK.



Over a period of six days, in the heat of the Namibian desert, Bren and the team covered 330km. This challenge pushed Bren to the limits of his mental and physical abilities but they did it raising over £4k in the process!

IN MEMORY

Kieron Else completed a charity truck pull for METUPUK in memory of Connie Johncock who was a founding Trustee. This incredible achievement took a significant amount of training and commitment and raised an amazing amount for the Charity.

We are so proud of Connie's family and friends who celebrate and honour her legacy in so many ways.



Louise Furneaux, a former Trustee of METUPUK who died in 2022, was the inspiration for her twin sister Sarah to raise over £1,300 with a challenge over 31 days. "I was 1 minute older than Lou, now I'm a year older, so in honour and loving memory of Louise and our first birthday apart I am completing a reformer Pilates class for 31 consecutive days". Louise's family also support METUPUK through the corporate partnership with their business Giveacar, a social enterprise that turns unwanted cars into donations for charity. They continue to raise funds for METUPUK ensuring that we can continue with our work across the UK.

Mary Huckle's family and friends came together to raise funds for METUPUK in her honour, after dying in May 2023. She campaigned for better access to treatments and trials for MBC patients and was a significant figure in the MBC community.



METUPUK has historically not had a fundraising strategy in place but with the introduction of Fundraising Trustee, looking forward into the next financial year the Charity seeks to build stronger financial foundations which it can forward plan activity around. The introduction of smaller, regular donations to the Charity along with organised fundraising events are in planning.



OUR FINANCES

Financial Review

The Charity was registered on 9th November 2021 and has now completed a second financial year (running from 6th April 2023 to 31st March 2024). The Charity's income for this period exceeded expenditure by £17k, continuing to leave the Charity in a stable position at the end of the financial year.

The Charity has realigned its financial year so that, from 2024-25, it will run from 1st April to 31st March each year.

Expenditure summary 2023-2024

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, Metastatic Breast Cancer.

Through the use of restricted grant funding, the Charity arranged the first patient-led MBC Conference in the UK in June 2023. The Charity also funded a similar patient-led MBC Conference in Wales in October 2023 and the Charity's Strategy Conference in March 2024 as well as the Metastatic May and Breast Cancer Awareness Month (BCAM) campaigns.

Income summary 2023 - 2024

For the financial period, the Charity's main source of income was donations, comprising 65% of the total funding. The Charity also received a number of restricted grants, which were used to fund the MBC Conference in June 2023. The remaining income was generated through a small number of Charity-led fundraising activities.

STATEMENT OF FINANCIAL ACTIVITIES


RECEIPTS AND PAYMENTS ACCOUNTS

	Unrestricted	Restricted	2024	2023
Receipts				
Fundraising	3,082.59		3,082.59	73,044.38
Donations	50,760.96		50,760.96	13,823.83
Grant income	-	20,000.00	20,000.00	-
Other	3,809.20		3,809.20	15.00
Investment income	58.27		58.27	-
	<u>57,711.02</u>	<u>20,000.00</u>	<u>77,711.02</u>	<u>86,883.21</u>
Payments				
MBC awareness / Education events	38,932.82	15,143.57	54,076.39	22,339.35
Education/ Communications	327.44		327.44	600.05
Other costs	2,409.19		2,409.19	660.32
	<u>41,669.45</u>	<u>15,143.57</u>	<u>56,813.02</u>	<u>23,599.72</u>
Governance costs				
IT/ Website/ SM/ Telecoms	1,027.80		1,027.80	770.20
Insurance	171.55		171.55	179.32
Legal and governance costs	3,000.00		3,000.00	181.80
	<u>4,199.35</u>	<u>-</u>	<u>4,199.35</u>	<u>1,131.32</u>
Receipts less payments	11,842.22	4,856.43	16,698.65	62,152.17
Total funds				
Balance brought forward	62,152.17	-	62,152.17	-
Balance carried forward	<u>73,994.39</u>	<u>4,856.43</u>	<u>78,850.82</u>	<u>62,152.17</u>

STATEMENT OF ASSETS AND LIABILITIES

	Details	Unrestricted	Restricted	2024	2023
Cash funds	Lloyds bank	73,994.39	4,856.43	78,850.82	62,172.17
Liabilities	Accruals	750.00	-	750.00	-

Signed by one of the Trustees on behalf of all the Trustees.

 (Phil Southwell 20 January 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 be 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.

Looking forward to 2024-2025

Despite the ongoing cost-of-living crisis, the Charity's income levels have continued to exceed expenditure in the 2024-25 financial year.

ADMINISTRATION

List of current Trustees as at 1 January 2025:

Jo Taylor – Founder/Chair (Founding Trustee)

Emma Smith – Fundraising (appointed July 2023)

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

Nicky Goldthorpe – Secretary (appointed October 2024)

Phil Southwell – Finance and Technology (appointed November 2023)

Madeleine Meynell stepped down in November 2024 and Andy Figgins stepped down in December 2024.

The Charity's Registered Office is: 11 Lower Knoll Road, Diggle, Oldham OL3 5PD

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

METUPOK 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 2024.

Responsibilities and basis of report

As the charity trustees of METUPUK you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the METUPUK accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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 METUPUK as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

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: 15 January 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**

