

# METUPOK STRATEGY

*METUPOK is a patient advocacy group which aims to improve outcomes for those living with Metastatic Breast Cancer<sup>1</sup> (MBC). We want to see MBC downgraded from an incurable to a chronic illness. We support people living with MBC to gain access to the best medicines to help them live longer and improve their quality of life.*

*We work towards the day when MBC will be cured.*



## 1. Awareness and Education

**METUPOK will raise awareness that MBC is currently incurable. We will work to address the significant under-representation of MBC in the Pink celebratory marketing of many breast cancer fundraising campaigns.**

- Campaign to illustrate the realities faced by people living with MBC (e.g. #darkerpink campaign, metastatic May, #IAmThe31, #BusyLivingWithMets)
- Work alongside key stakeholders to promote the inclusion of MBC across all Breast Cancer awareness raising campaigns.

**METUPOK will educate policy makers, charities, and government bodies to ensure that MBC is an equal priority for funding, research, and innovation.**

- Work collaboratively alongside key organisations to secure increased funding of MBC research and innovation.
- Work in partnership with international stakeholders to consolidate global research and learning to influence improved MBC outcomes.
- Ensure MBC is represented on relevant Trusts or Boards of breast cancer organisations, with Patient Advocates as Trustees or Board Members.

**METUPOK will ensure people diagnosed with primary breast cancer understand and recognise the symptoms of MBC to support early MBC diagnosis and maximise treatment outcomes.**

- Promote the integration of the MBC infographic across all NHS Trusts, including Health Care Professional training - to inform people at key points of treatment, i.e., when adjuvant treatment is complete and subsequently at all follow up appointments and as part of the NHS End of Treatment Summary Report. (Greater Manchester Cancer gold standard)
- Embed the MBC Infographic across all relevant charities and health care organisations including the Macmillan Recovery Package.

1. Definition – MBC known also as Secondary Breast Cancer (SBC)– spread of breast cancer from primary site of breast (if detected) to remote part of the body – lungs, liver, bones, brain, which is incurable at the present time. Also known as ABC (Advanced Breast Cancer)

## 2. Research and Access to Drugs

### **METUPUK will work to make breast cancer clinical trials easier to access and more equitable for MBC patients.**

- Advocate with life science companies to increase the number of MBC trials in line with the number of MBC patients and recognise the real potential to extend and save lives.
- Monitor to what extent life science companies' clinical trials and treatments align with Cancer Outcomes and Services Dataset (COSD) Data and outcomes.
- Work together with breast cancer charities to provide an equitable and improved trial system for all people diagnosed with MBC.
- Produce and maintain METUPUK clinical trials database that collates relevant data to provide ONE comprehensive trials data set that is updated monthly.
- Campaign for patient involvement in clinical trial design and work with pharmaceutical companies to challenge unnecessary trial restrictions and inflexibility.
- Campaign for the "right to buy" drugs and not at an inflated price

### **METUPUK will lobby regulatory authorities to speed up the drug approval process for new MBC drug treatments.**

- Submit evidence to NICE & the SMC for drug and technology approvals.
- Work with key stakeholders (i.e., NICE, NHS and pharmaceutical companies) to co-operate meaningfully to reduce the timescales for treatment access.
- Ensure MBC patients are getting access to drugs through compassionate access and individual funding requests.

### **METUPUK will maximise application of technological advances to improve collation and analysis of data and statistics for MBC. We will encourage medical decision makers to use the information to better inform treatment decisions.**

- Strategic planning around data collection in MBC with Oxygen. We will identify targets to improve survival outcomes for MBC patients.

### **METUPUK will campaign for increased funding for fundamental scientific research into MBC.**

- Advocate with breast cancer research charities to ensure that research funding allocated to MBC projects is in line with the number of MBC patients (ie. at least 30%)
- Campaign for greater transparency in MBC research funding
- Produce information and guidance on the different research charities funding MBC research for patients wishing to fundraise for MBC research.

### **3. Patient Treatment and Care**

#### **METUPUK will work to ensure that MBC patients throughout the UK have access to the best treatment options and highest standard of care**

- Work with stakeholders to encourage clinical professionals to safeguard & provide a holistic approach for MBC patients by adopting the Macmillan Recovery Package as part of their practise.
- Campaign for an increase in MBC clinical nurse specialists to support UK patients. Work with charities and stakeholders to demand the UK-wide roll out of CNS's within a specific and urgent timeframe.
- Ensure MBC patients throughout the UK have the appropriate opportunities to access surgery or radiotherapy.
- Challenge surgical pathways and campaign for access to new surgeries (e.g. GMCancer are addressing liver and bone pathways for MBC).

#### **METUPUK will support MBC patients in understanding treatment and lifestyle options and how they can live well with MBC.**

- Collaboratively work with the key stakeholders to ensure swift access to new innovative ways of supporting MBC patients.
- Disseminate research information to increase awareness to MBC patients. Ensure that stakeholders are making this information available and easily accessible.

#### **METUPUK will provide support to family members and friends of MBC patients**

- Supporting Friends and Family with our online group

## How METUPUK spend our charitable funds

- Funding our awareness campaigns (e.g. generating professional content including videos and graphics, sponsored social media posts)
- Supporting our patient advocates to attend conferences
- Assisting with speaking engagements on behalf of METUPUK
- Delivering training sessions for our advocates
- Organising information days for MBC patients
- Strategy development days
- Charity running costs (AGM, accountant)

## Our Achievements so far

### Media Campaigns

- #BusyLivingWithMets campaign
- #IAmThe31 campaign
- #MetastaticMay campaign in May 2021 resulted in increased activity across all platforms.
- #MetastaticMay 2022 is currently underway.
- #2ndsOnThe2nd campaign
- #DarkerPink campaign for BCAM 2021
- #DarkerPink figures currently on tour across the UK

### Awareness

- SBC infographic signposted by NHSE and included in End of Treatment summary reports for primary patients in GMCancer (hoping to be rolled out in other areas)
- EOT informing GPs to create awareness of MBC
- Gateway C - infographics included in the recurrence module for GPs for primary patients
- Infographics translated into 11 different languages

### Drug Access

- NICE submissions for
  - Enhertu (fam-trastuzumab-deruxtecan-nxki),
  - Tukysa (tucatinib),
  - Trodelvy (sacituzumab govitecan-hziy)
  - Piqray (alpelisib)
  - Keytruda (pembrolizumab)
- Helping to support patients across the UK
- Provided advocate training sessions on NICE health technology approvals

### Patient Support and Care

- Established friends and family support group