



# Giving Hope To Those Living With Secondary Breast Cancer

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*Impact Report 2022 - 2023*



# Chair's Statement

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When we step back to survey the work of Make 2nds Count over the past year, I feel immense gratitude for the opportunity to share some of these remarkable achievements with you. This report is more than simply a collection of statistics or numbers – it reveals the ways that our work together supports so many patients and their families and delivers on our mission to provide hope in the face of secondary breast cancer.

One pillar of our mission is to fund research focused on secondary breast cancer and quality of life for patients. The LIMBER study, which we funded with Dame Lesley Fallowfield and the SHORE-C group, measured patients' important needs and preferences for information from their medical care providers. We have also announced our largest funding award to date: over £219,000 over three years to study screening protocols for patients with secondary HER2+ breast cancer.

We have also seen tremendous growth in our Patient Trial Advocate (PTA) service, which allows any UK patient to meet with one of our three specialist nurses to learn more about clinical trials and request a bespoke search for any UK trials which might be suitable. The PTA team also hosted events in Maggie's Centres throughout Scotland, meeting groups of patients and helping them feel informed and empowered to discuss clinical trials. We've also launched a database of UK clinical trials focused on secondary breast cancer that is patient-focused and regularly updated.

Patients are at the heart of everything we do, and I'm delighted that we've been able to offer more resources to support patients in the past year. Our retreats have proved to be incredibly popular, and we have expanded our online and in-person meetings of Tea & A Chat. We provide opportunities for peer-to-peer support, and we offer Wellbeing Week seminars with experts on yoga practice, menopause, travel insurance, and more that is tailored for our patient context.

None of this would be possible without the determination and creativity of our staff, whose hard work day in and day out turns our mission into reality. And I must acknowledge the extraordinary community of supporters, donors, ambassadors and champions who believe in the importance of our mission and who are determined to make a difference. On behalf of the Board of Trustees, thank you for every generous donation: whether financial, or of volunteer hours and/or raising awareness of the charity. Make 2nds Count continues to thrive because of you and everything you do.

The need is great. Every day, more patients across the UK will be diagnosed with incurable secondary breast cancer. Make 2nds Count is here to offer them hope – hope through ongoing research, empowering education and meaningful support. While we celebrate our accomplishments, we know there is more work to be done. We invite you to be part of this important, inspiring project of hope.

*Professor David Cameron*

Professor of Oncology and Director of Cancer Services, NHS Lothian at the University of Edinburgh

# What Our Community Say

"Patients share that they feel positive about the future and feel reassured that all options have been explored for them, something which I feel is so important to patients and families in the presence of a life-limiting illness."

**Dr Caroline Michie, Lead Clinician for the South-East Scotland breast cancer clinical trial team, on referring patients to the Patient Trials Advocate service**

"Incredibly grateful for the support from the charity, this project is long overdue for our patients and with your help, we can finally undertake the work."

**Prof Sara Meade, University Hospitals Birmingham, following the 2022 funding call**

"I felt part of something that made me feel safe and supported and understood by all those around me. It made me feel less scared and isolated and ready to start being me again. I feel since the retreat I can look forward to things and living life and not having to always have anxiety about my diagnosis."

**Mandy Smith, speaking about her experience of our 2nds Together Retreats**



# What Is Secondary Breast Cancer?

Secondary breast cancer, also known as metastatic, advanced or stage IV breast cancer, is a cancer that has spread beyond the breast to other parts of the body. Parts of the body affected are usually the bones, liver, lungs, brain or the skin.

Secondary breast cancer can be treated but it cannot be cured. Treatments aim to control and slow down the disease to enable patients to have the best possible quality of life for as long as possible.

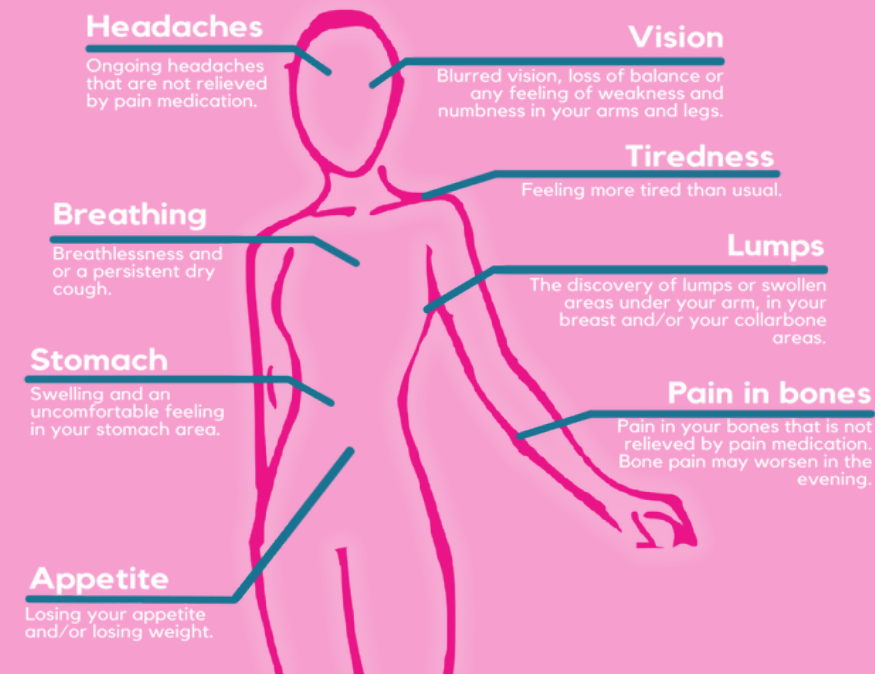
Every year around **11,500** women and **85** men die from breast cancer in the UK – that's nearly **1,000** deaths each month, **31** each day or one every **45** minutes.

Breast cancer is the **fourth** most common cause of cancer death in the UK.

Breast cancer is a **leading** cause of death in women **under 50** in the UK.

There are an estimated **61,000** people living with secondary breast cancer in the UK. In around **5%** of women, breast cancer has already spread by the time it is diagnosed.

## Signs & Symptoms of Secondary Breast Cancer



If you have any concerns of your own, then please seek out medical advice from your GP or doctor.

# Our 2022 Impact

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littlelifts boxes sent to patients  
*up from 217 in 2021*



Tea & A Chat participants  
*up from 110 in 2021*



Retreat attendees  
*up from 40 in 2021*



2nds Support Hub users  
*up from 600 in 2021*



People reached on social media  
*up from 383k in 2021*



# Our Research

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The aim of our research pillar is to fund projects that are led by patient experience and contribute to advancing an increased quality of life. There is no cure currently for secondary (metastatic) breast cancer, so it's about finding treatment that works to give the best quality life for as long as possible.

## LIMBER

UK survey measuring informational needs and quality of life in women living with secondary (metastatic) breast cancer.

Project status: **Complete**

### Key findings:

- Doctors use different terms at different times to describe disease, but the most preferred by patients is Secondary Breast Cancer
- 87% prefer verbal information
- 67% indicated that their doctor/nurse did NOT address their emotional needs
- 45% said that their doctor/nurse did NOT consider their lifestyle/culture
- One respondent said "It is very disappointing that there has been no attempt to consider the impact it (my illness) has had on, or support for, my family."

## MSCB

A national study of the experiences, information needs and attitudes to clinical research of patients living with secondary breast cancer in the UK.

Project status: **Complete**

### Key findings:

- Only 23% of clinicians raised clinical trials with patient
- One respondent reported "Oncologist very unsupportive. She said most trials fail and should only ever be a last resort."
- Only 31% of patients asked clinical team about trials
- Patients are aware of benefits of trials but some concerns with side-effects, costs and understanding about the trial
- Patients happy to seek out information from clinical team and some would use trial register
- Patients are willing to travel

# 2023 Research Project

We have awarded our largest funding award to date: £219,560 over 3 years. We hope the funding of this project will over time make a difference to patients with HER2+ secondary (metastatic) breast cancer.

## HER2-CNS Surveillance

A study of the feasibility and effectiveness of additional surveillance of the Central Nervous System (CNS) for women and men with HER2+ secondary breast cancer.

Project status: **Launching in 2023**

Study outline:

- The trial will recruit 69 women and men with HER2+ breast cancer with no history of brain metastases
- After MRI screening, patients will be randomised to further surveillance with 6-monthly scans for 1 year, or none
- Recruitment opening in 2024



Dr Carlo Palmieri  
Professor of Translational Oncology at The University of Liverpool & Consultant in Medical Oncology at The Clatterbridge Cancer Centre NHS Foundation Trust in Liverpool

Thanks to co-funding from **Breast Cancer Ireland**, patients in the Republic of Ireland will also be able to participate in this vital research. "We're excited to see the impact of this collaboration between some of the finest research experts in the world, and firmly believe that research and information sharing such as this are the best opportunity for scientific breakthroughs in relation to this ever challenging disease."

**Aisling Hurley, CEO, Breast Cancer Ireland**

# Our Education PTA Service

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The aim of the Patient Trial Advocate service is that every UK patient with secondary (metastatic) breast cancer feels better informed about clinical trials, and feels confident and empowered to discuss them with their clinician as part of their treatment pathway.

In 2022 we recruited two new part-time nurses to the Patient Trial Advocate service, growing the team from one to three. Our nurses are currently based in NHS Lothians, NHS Borders and NHS Highlands covering all of the UK. Our experienced NHS nurses help answer patient questions about clinical trials, search the UK secondary breast cancer trials databases for the patient's eligibility, and support patients in discussing those trials with their clinicians.

- Since May 2021 the team has supported **259 patients** – 175 in England, 64 in Scotland, 16 Northern Ireland and 4 in Wales.
- We have partnered with **Breast Cancer Now** and **Maggie's Centres** to run sessions on the service for healthcare professionals and patients
- In 2023 we will run **one educational session per month** through our partners, and aim to support **30 patient referrals per month**



Each purple dot on this map represents an area across the country where someone has accessed our PTA service!

"The service was fantastic and really helped me talk through at a very frightening time. Wish I'd had this service earlier!"

**PTA Service User**



# Our Support

Make 2nds Count's mission is to enable patients to have the best possible quality of life for as long as possible. With a focus on quality of life, our support programme helps patients and families affected by this incurable disease by informing, sharing, and offering practical advice and support.

- '2nds Together': Our private, moderated Facebook group. Membership has increased to over 1K.
- Launched two sub-groups: Craft Club and Book Club.
- 'Tea & A Chat': Our in-person monthly sessions grew considerably in 2022, with groups launching in London, Boston/Lincoln and Glasgow.
- Retreats: We welcomed a total of 68 patients across three different locations - Cornwall, Glasgow and Liverpool.
- Wellbeing Week 2022: We hosted expert panels and discussions on the subjects of Menopause, Sex and Exercise. The week had 61 sign-ups.



"It's been about three months since we met and I'm using the skills learnt and feeling so much better. In fact it's been noticed by others. The confidence you helped unlock has given me a new outlook and positivity that I didn't know was possible in our situation."

**2nds Together Retreat Attendee**

"One day, about three weeks after diagnosis, I was having a particularly bad day and in my desperation, I posted on the Facebook page, asking for help and support to face the awful fear of dying early and leaving my children. I went for a long walk and by the time I got back, about 30 women had replied with messages of love, support and crucially, hope! The impact these messages had on me and my husband was immediate and transformational. We had hope!"

# Raising Awareness

Make 2nds Count is growing in every way - our team, increased fundraising and new research projects. We're reaching more and more patients across the UK, adding new support services and building our network across the NHS, businesses and charities.



This year we worked tirelessly to raise awareness of Make 2nds Count and secondary (metastatic) breast cancer. We launched our PTA services and coordinated a gorgeous Shine a Light campaign during Breast Cancer Awareness Month, both UK wide. Through print, online and broadcast media, we have managed to share our message with 967,599,731 people! Across social media we reached over 470,000 people, and over 3,500 new people joined our online community.

We took our campaign to raise awareness of secondary breast cancer to the Scottish Parliament from the 29 Nov. to the 2 Dec, 2022. We staged an exhibition highlighting the shocking toll of the disease, the signs of secondary breast cancer and our pioneering Patient Trials Advocate service (PTA).

**Thank you to everyone who has and continues to support the work we do to help secondary breast cancer patients and their families.**

## Karen Henderson Legacy Fund

Karen Henderson passed away in 2021 from secondary breast cancer. Her family and friends launched the Karen Henderson Legacy Fund in her memory to support patients to improve their health and wellbeing.

Through 2022, the fund has raised an incredible £56,328.46 and funded several projects.



**22 yoga sessions**



**420 Little Lift boxes**

This year the Karen Henderson Legacy Fund is supporting the Edinburgh Tea & A Chat group.

“What Karen benefited from through the charity was the community and the sense of family that Make 2nds Count brought, so this event is a great opportunity for people in a similar position to get together and support one another.

Karen would have been so pleased to be supporting this great initiative.”

**Alistair Henderson, Karen's husband**

# Income & Thanks

What an incredible year 2022 has been for fundraising at Make 2nds Count. We are so grateful for all your support and for always going above and beyond to raise vital funds for those affected by secondary (metastatic) breast cancer across the UK.



Looking over the past year, it's almost impossible to pick just a few highlights! From birthday fundraisers, cake sales, quizzes and clothes swaps to Daisy's Taxi Rally and the Make 2nds count Skydive, it's amazing to see what our supporters are doing to raise awareness and funds!

On top of that, we've had incredible support from our charity partners, Dalkeith Country Park & Restoration Yard, SoftCat and Lounge Underwear, to name a few. These partnerships have helped us connect with new audiences and raise awareness of the signs and symptoms of secondary breast cancer.

With wild swimming, marathon running, Ben Nevis climbs and everything in between, we are constantly in awe of our supporters' strength, determination and imagination.

**Thank you so much for making 2022 such an epic year - we can't wait for 2023!**

## Thank You!

A massive thank you to the following who have donated or raised over £3,000 for Make 2nds Count and for everyone who has and continues to fundraise for us. We can't do it without you.

Anne Henderson  
Challenge Breast Cancer  
Emma Tagliavini  
Kirsty Fleming  
Lounge Underwear  
Natalie Nelson  
Petroleum Experts Ltd  
Pink Ribbon  
People's Postcode Lottery  
Rhona Callander  
Scott Macpherson  
Shirley Roche  
Tansy Main  
Westfield Health

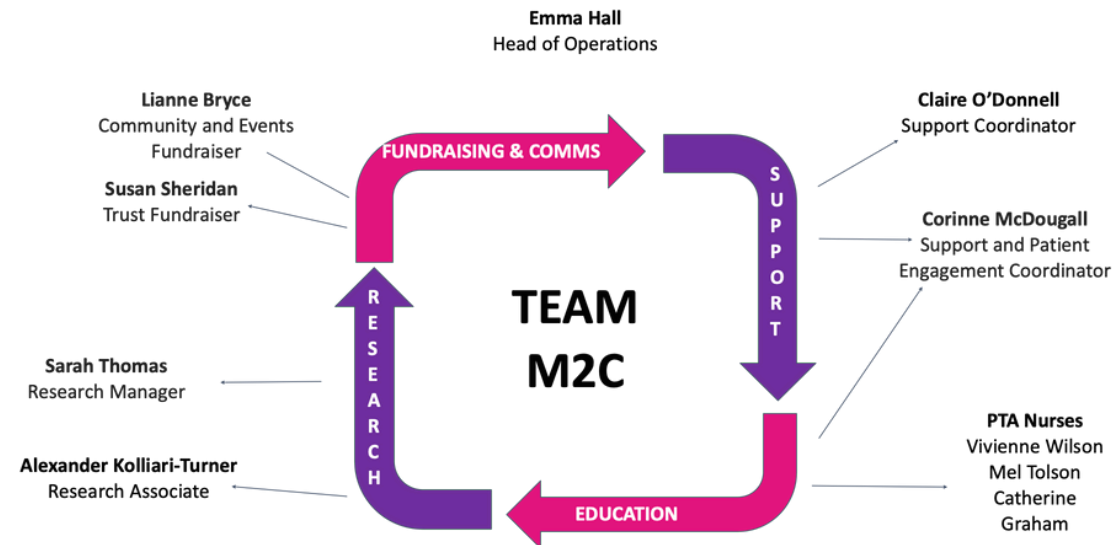


# Our Team & Trustees

## Trustees

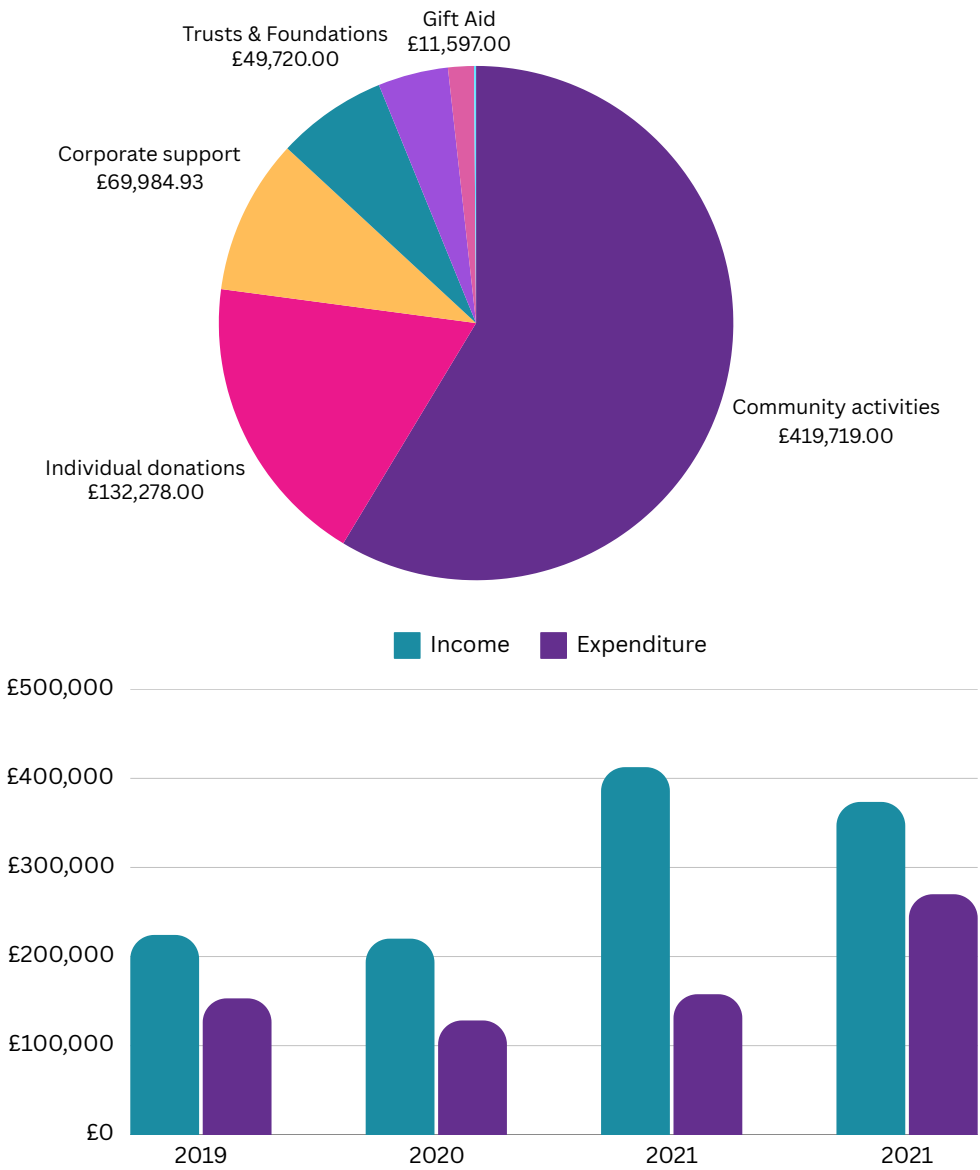
Professor David Cameron, Chairperson  
 John Ward, Treasurer  
 Heather Moffitt (*SBC patient*)  
 Ian McCarlie  
 Joanne Lacey  
 Lesley Stephen (*SBC patient*)  
 Dr Peter Canney

## Our Team



# Financial Performance

	Unrestricted Funds	Restricted Funds	Year Ended 31/12/22 Total Funds	Period Ended 1/5/21 to 31/12/21 Total Funds
	£	£	£	£
<b>INCOME AND ENDOWMENTS FROM</b>				
Donations and legacies	515,217	180,269	695,486	369,813
Other trading activities	85,875	-	85,875	3,716
Investment income	323		323	30
<b>Total</b>	601,415	180,269	781,684	373,559
<b>EXPENDITURE ON</b>				
Raising Funds	135,334	134,767	270,101	96,679
<b>Charitable Activities</b>				
Advancement of Health	6,840	6,300	13,140	173,269
Activity Support	256,879	24,336	281,215	-
<b>Total</b>	399,053	165,403	564,456	269,948
<b>NET INCOME</b>	202,362	14,866	217,228	103,611
<b>RECONCILIATION OF FUNDS</b>				
<i>Total funds brought forward</i>	426,150	95,362	521,512	417,901
<b>TOTAL FUNDS CARRIED FORWARD</b>	628,512	110,228	738,740	521,512





# Governance

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Make 2nds Count is a Scottish Charitable Incorporated Organisation (SCIO). Its structure, governance and management are set out in the constitution which is regularly reviewed by the board of trustees.

To build on previous successes, a decision has been taken to outline a new strategic vision for the organisation. It remains our intention to continue giving hope through our three charity pillars of Research, Education and Support to those affected by secondary breast cancer.

## Reserves Policy

The board continues to review its reserves policy. Current policy is to maintain a cash reserve equivalent to approximately six months' operating costs to bridge the gap between income and expenditure and to secure a ring-fenced reserve for the quarterly commitments to our research partners.

The current free reserve is £181,967. This equates to approximately six months. Should the charity be forced to wind up, the proceeds will be donated to a like-minded charitable cause.

## Risk Management

Either the board – or its four subcommittees – meet monthly and all provide detailed reports. Risk review is an important agenda item for the trustees, particularly as we continue to navigate uncertain times. The plans outlined in our strategic vision come with some risk, but these have been minimised by recruiting additional resources within the staff team and increasing the size of the board of trustees.





## **Make 2nds Count**

GyleWorks

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*Registered Charity Number: SC048268*