

Support for those living with incurable BC

Louise Perkins Foundation t/a Sweet Louise

OVERVIEW: There is a lack of support for patients with ABC/mBC in New Zealand and life expectancy is low for these patients. This initiative offers a holistic programme of social, psychological, emotional, practical and financial support to enable patients with ABC/mBC to live as well and as long as possible.



Area of focus:

Support for patients with ABC/mBC

Target population:

All women diagnosed with ABC/mBC annually in New Zealand

Objectives: Provide practical, emotional, social and financial support for patients in New Zealand living with ABC/mBC and improve life expectancy and quality of life for these patients

Unmet needs addressed:

- Lack of support for patients (men and women) diagnosed with ABC/mBC outside of required medical care
- Low life expectancy (~16 months from ABC/mBC diagnosis)

Key components:

- A telephone helpline and a guidebook on living with ABC/mBC
- Each patient in the programme receives \$500 financial assistance annually and \$200 'family time' assistance
- Group meetings, individual home or hospital visits and access to a dedicated trained health professional

Challenges: Delivering a tailored approach can be challenging within the constraints of the funding available and the initiative relies on referrals from oncology teams, but awareness differs across each district

Outcomes: The initiative currently supports 742 patients across the whole of NZ, who have a life expectancy of ~2 years (compared to a country average of 16 months), improved connectivity, and reduced social isolation, and financial hardship. The initiative delivers a social return on investment of \$5.70 for every dollar spent based on improved physical and mental health of participants

Development: The initiative is delivered by a team of 8 and guided by an oncologist and medical advisory team

Cost: >€30,000 (financial support from >230 companies; >\$1,000,000 sponsorship & grant funding annually)

Timeline: 15 years (2005–ongoing)

Targeted to reach: >300



Louise's Story

The Louise Perkins Foundation was established in 2005 by Scott Perkins, named after his wife Louise who passed away in 2004 after living for ten years with incurable breast cancer.

Louise Perkins lived with absolute positivity and went about life with cancer as a small part of living rather than as a main focus of her life.

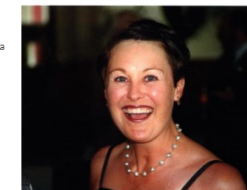
Louise was diagnosed with breast cancer at age 27. She had just graduated and recently married. Louise had everything to live for and went through all the recommended treatments with a promising recovery.

However, at 29 years old, she was told that the cancer had advanced to a secondary stage and accompanying her diagnosis of metastatic breast cancer, she was given just two years to live.

Louise received excellent medical care but knew that while this was necessary it was not enough. She filled her life with reasons to live, tending her mind, body and her spirit and discovered a myriad of ways that helped her deal with the challenges of an incurable cancer.

Exceeding all expectations, Louise lived another full and vibrant 10 years which her oncologist stated as "off the charts".

Over the ensuing 10 years, Louise had an overwhelmingly optimistic attitude with a determination to live life to the fullest. She lived with absolute positivity, getting on with cancer as a small part of living rather than a life with cancer.



For more information:

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Based on written submission from Catrin Devonald, Sweet Louise, 2020. The Hard-to-Reach ABC/mBC Communities Toolkit was developed as a collaboration between Pfizer Oncology and the ABC Global Alliance, with funding and support provided by Pfizer. ABC Global Alliance members and Pfizer colleagues were invited to submit breast cancer community-based initiatives that address specific needs of underserved patient populations with advanced/metastatic breast cancer. Initiatives were evaluated against criteria determined by a steering committee with members from both Pfizer and the ABC Global Alliance. Initiatives were selected for inclusion in the toolkit to highlight best practices in addressing the unique needs of this patient population. All organizations who submitted their initiatives for consideration have provided permission for the initiative information to be included in the toolkit and shared publicly. Pfizer and the ABC Global Alliance bear no responsibility for the contents of the toolkit.

| Ethnic, religious, indigenous/native populations and/or other historically marginalised groups | Younger patients | Older patients | Men | LGBTQ+ patients | Low health knowledge patients | Patients who lack an adequate caregiver or support system | Patients who mistrust conventional treatments | Low income patients | Patients a long distance from a specialist centre | Patients with uncontrolled comorbidities | Mental health patients |