

PINK RIBBON PRESS

Autumn 2015

HOST A BREAKFAST AT
www.pinkribbonbreakfast.co.nz

Published by

THE NEW ZEALAND
 BREAST CANCER
 FOUNDATION

KIWI WOMEN deserve clinical trials

“Can I go on a clinical trial?” That’s the question we’re often asked, particularly by women with advanced breast cancer, for whom existing treatments are no longer working. Tragically, the answer is most often: “No.”

New Zealand has a shockingly low rate of clinical trials – only about 2% of breast cancer patients are involved in one – yet trials are often the only way to access expensive new drugs, and studies show that patients on trials generally do better than non-trial patients, even if the new drug doesn’t work.

We need more trials for more women! The reasons for the lack of access to trials are complex, but we’re determined to do something about it. The starting point is making sure that women can easily find out about trials available anywhere in NZ or Australia. Many women tell us they’re happy to travel to a trial, but their doctors assume they won’t want to, or they aren’t aware of trials that might be relevant.

The internet is the logical place to look, but information about clinical trials is spread across many different websites, is not sorted by location, and can require scrolling through hundreds of irrelevant trials to find one that might suit. And when you do find one, there’s a good chance the information is out of date.

That’s why we’ve contacted hundreds of trial coordinators around Australia and NZ, to find out exactly which trials are currently open to new patients, and what trials are starting soon. The result of this work is our new NZBCF Clinical Trials Database available soon at www.nzbcf.org.nz/ClinicalTrials.

Information is categorised for early or advanced breast cancer, by cancer type (e.g. ER+, Triple Negative), and we provide a basic description of each trial plus contact details for more information. We also have information on supportive care and rehabilitation trials.

Now that we’ve made it easier for women to access information about existing trials, our next step is to encourage our hospitals to run more trials, and to open them to more women. That won’t be easy, but it’s vitally important.

We look forward to telling you about the progress we’re helping to make in this area.



“It would mean the world to me and my son Kane if I could go on a clinical trial here in NZ”

- Rochell Adams, a single mum with Stage IV advanced breast cancer, needs to raise \$50,000 to access drug treatments in Germany.

Hot Topic

Access to new drugs woeful

A new report shows that New Zealand ranks nearly last (19th) out of twenty OECD countries for access to “first-in-class” drugs – that means new, usually expensive drugs that have been given priority approval for patient use following clinical trial. Even financially strapped Spain and Ireland beat New Zealand in funding the best and latest treatment drugs.

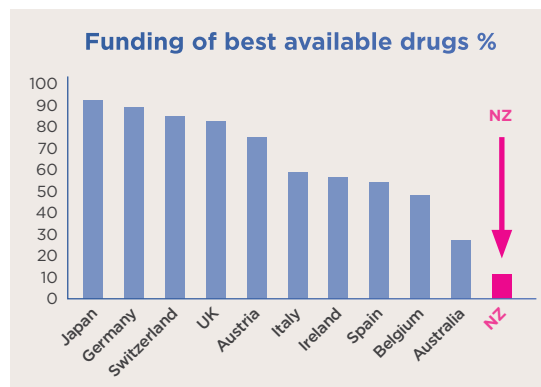


Table: Proportion of approved first-in-class drugs funded for patients during 2009-2014. Source: Medicines Australia ‘Compare’ March 2015

Actual numbers: Proportion of approved first-in-class drugs funded for patients during 2009-2014

1st	Japan	93%
2nd	Germany	88%
3rd	Switzerland	83%
4th	UK	81%
5th	Austria	76%
10th	Italy	58%
11th	Ireland	56%
12th	Spain	52%
15th	Belgium	48%
18th	Australia	27%
19th	New Zealand	11%

‘Desperate for the latest drugs’



Evangelia Henderson

Women diagnosed with advanced or secondary breast cancer face a battle to prolong their lives from a disease that is incurable. New drugs available overseas, are achieving amazing results for some women...but those drugs are too expensive for NZ's public hospitals. We don't get them until years after countries like Australia. The only way our women can get hold of these drugs is through clinical trials, but there aren't enough of these trials running in NZ. We're working hard to improve access to drug trials for Kiwi women. Your donations are helping to fund the first information database of Australasian clinical trials accessible soon on The NZBCF website.

It also tracks their lifetime outcomes. This year, a major project for the Foundation together with the Ministry of Health, is consolidating the registers into one, enabling national coverage and preparing for future links to genomic data. Of course, the value of this rich data only emerges when it's analysed by doctors and researchers. So this year we launched an innovative research competition, aiming to develop a pipeline of new breast cancer studies. We'll be closely tracking the progress of these studies.

is not just a 'nice to have' – studies suggest that depression can reduce breast cancer survival rates.

We thank you for your ongoing support for those living with breast cancer.

Evangelia

Evangelia Henderson (CEO)

How your donations are being put to good use

Fifteen years ago, The NZBCF embarked on funding the Breast Cancer Patient Registers. The four registers – Auckland, Waikato, Wellington and Christchurch – cover 66% of NZ patients, informing us who gets breast cancer and how they're treated.

Our new NZBCF Counselling is a free service for anyone with breast cancer. Initially funded by the '1000 Tees for 1000 women' campaign, free counselling's accessible face-to-face or by phone or Skype. We hope it will support women everywhere, especially those in remote areas. Often it's helpful to talk issues over with someone not personally connected to your life. Counselling



It frustrates me that those of us with secondary breast cancer get forgotten about. We did the hard yards with treatment, changed our lifestyles and the cancer still came back. There is not enough research done for the group of people who are still trying to live and contribute to society whilst coping with an incurable disease.

The signs are getting through

During April, The NZBCF invested in education advertising aimed at raising awareness amongst women of the possible signs of breast cancer. Research indicates the 'Real Signs' TV and radio commercials, fronted by actress Geraldine Brophy, have been effective in raising awareness that breast cancer doesn't always present as a lump. That skin changes (dimpling or redness, unusual breast pain, changes in the nipples or breast shape and size) can all be signs of breast cancer too.

Janice Wood, NZBCF Specialist Nurse, has had plenty of feedback that the graphic advertising is making a difference.

"Younger women especially have been ringing our advice line after seeing the ad, worried about breast changes," she says. "I tell them that while it's important to see their doctor, not to panic as most breast changes aren't cancerous."

Visit www.anychanges.co.nz to view the 'Real Signs' TV Commercial.



the fact is this campaign brings so much awareness to breast cancer, it was one of my main reasons for getting my mammogram October last year when I turned 45...it saved my life. So thank you!!!!!!

Did you know...

that around 90% of women with breast cancer have **no** family history of the disease? So that's why all women need to be vigilant around their breast health from the age of 20. However, if your mother and/or sister was diagnosed younger than age 50, then your risk of breast cancer is higher than most.



ASK OUR NURSE

Call our free advice line **0800BCNurse (0800 2268 773)** to speak to a breast specialist nurse or email breasthealth@nzbcf.org.nz

FASTER NEWS!

Sign up for Pink Ribbon Express, our e-news at www.nzbcf.org.nz



Join us at www.facebook.com/NZBreastCancerFoundation



Follow us @nzbcf on Twitter

New support services...

▶ thanks to you

Your generosity has enabled The NZBCF to fund new support services aimed at helping New Zealanders with breast cancer. More importantly you're helping to make a difference in your very own community.

▶ Free counselling now available

The NZBCF has launched a free counselling programme offering three free one-on-one professional counselling sessions to people at any stage of their breast cancer treatment, "That might be just after diagnosis, during or after treatment or if a woman's breast cancer has advanced," says NZBCF CEO Van Henderson.



"Just as all breast cancers are different, women's support needs are different too."

While some hospitals do provide access to counselling, it's not available uniformly around the country. The counselling service will be available face-to-face in most areas, but also over the telephone and via Skype for women who would struggle to attend a physical appointment.

Women need to be referred for counselling by their specialist physician, breastcare nurse or GP. Once the referral is approved, women will have online access to profiles of qualified counsellors in their area and can book an appointment with the counsellor of their choice.

NZBCF Counselling is funded entirely by donations. To download a referral form or for more information, visit www.nzbcf.org.nz/freecounselling or call **0800 BCNurse (0800 226 8773)**.

▶ IN YOUR NECK OF THE WOODS

Jump online to see how your donation is making a difference in your region. From funding innovative research to transporting women to treatment and enabling the Pink Caravan Tour to reach small towns, The NZBCF is committed to helping all New Zealanders affected by breast cancer. Click on your region at www.nzbcf.org.nz/communityimpact



PINK CARAVAN 'ANGELS' NEEDED

The next Pink Caravan national tour kicks off mid September. If you're willing to help our breast nurses set up quickly when they roll into your town, please email diannes@nzbcf.org.nz.



▶ Next Steps: FREE classes

Designed to help rebuild strength and self-confidence, PINC Next Steps is a new group-based gentle exercise class run by a qualified physiotherapist over 10 weeks. It's designed for women who have undergone surgery and completed their breast cancer treatment.

The NZBCF is funding places on the Next Steps Programme for low-income women in the following regions: Orewa, Albany, Mt Eden, Hamilton, Mount Maunganui, Rotorua, Napier, Wellington, Nelson, Timaru, Christchurch, Dunedin and Invercargill.

The NZBCF also provides funding for individual physio treatment for women currently undergoing treatment. To find out more about both Next Steps and individual PINC physio, visit www.pincandsteel.com/programs

Fancy India in 2016 ?

Imagine trekking the foothills of the Himalayas then unwinding with yoga and meditation in Rishikesh, the 'Yoga Capital of the World'. Join The NZBCF on the adventure of a lifetime whilst helping Kiwi women. With every step you take, with every 'ommm' you make, you will bring The NZBCF one step closer to preventing women from developing and dying from breast cancer. For more information visit www.nzbcf.org.nz/india.



Sign our 70+ Petition



The NZBCF is calling on the government to extend the free screening program from 69 to age 74. Please sign our petition as research indicates that the breast cancer risk for a woman in her 70s is even higher than in her 50s. If you're in good health, The NZBCF urges you to consider paying for a mammogram every two years after your free screening ends at age 69.

Visit www.nzbcf.org.nz/OlderWomen.

- **DOWNLOAD AND SIGN THE SCREEN 70+ PETITION**
- to extend free screening to age 74.
- **WATCH THE VIDEO**
- featuring Lorraine Downes and her mum, 'Breast Health for Older Women.'
- **DO SCREEN70+**
- a decision aid to help you decide whether to continue with mammograms.

Men: You can get breast cancer too.

Around 20 men are diagnosed with breast cancer in New Zealand every year. Most men don't realise they can get breast cancer or that their risk is higher if a close family history of breast or ovarian cancer exists. So that's why our Educators have a new resource in their kit aimed at making men 'breast aware'. Find out more at www.nzbcf.org/men.



EDUCATION

Works!

Breast health education resources are available free of charge thanks to your donations. To order or download, visit www.nzbcf.org.nz/resources or look for the "Order Resources" tile on the home page.

ORDER RESOURCES

NATIONAL
COMMUNITY
EDUCATION



THE NEW ZEALAND
BREAST CANCER
FOUNDATION

Get breast
changes
checked out
from age

20

Start
mammograms
regularly
from age

40

Your risk
is still
high from
age

70

LEAVE A LASTING LEGACY



Find out about leaving a gift in your will to the NZBCF. Your generosity could gift someone their life.

Name _____

Contact Telephone _____

Address _____

Email _____

Call 0800 902 732 or email patriciab@nzbcf.org.nz for more information

Yes!

I would like to be contacted by The NZBCF Bequests Manager.

Post to NZBCF
PO Box 99650
Newmarket,
Auckland 1149

Breakfasts could fuel a breakthrough



May is Pink Ribbon Breakfast month so Lorraine Downes has asked Kiwis to host or attend breakfasts in May, to raise funds for The NZBCF.

Proceeds from this year's Pink Ribbon Breakfasts will go towards breast cancer research, including new drug development, research into the genetic factors that contribute to cancer spread, and support for clinical trials that provide access to new and expensive treatments.

"Research is key to improving Kiwi women's survival," said Lorraine Downes, who is an NZBCF ambassador and former Miss Universe. Her mother was diagnosed with breast cancer in 2012 and underwent successful treatment for the disease. "The advances that saved my mum started with research projects like the ones the NZBCF is funding today."

The latest statistics show that 73% of Kiwi breast cancer patients are disease-free 10 years after diagnosis⁽¹⁾. But still, more than 600 women die of breast cancer each year. ⁽¹⁾

"This year, our goal is to raise \$1.5 million from the Pink Ribbon Breakfast campaign", says NZBCF CEO Van Henderson. "There are exciting research opportunities coming up, and we want NZ women to be among the first to benefit. We're so grateful to our Pink Ribbon Breakfast hosts, guests and sponsor Kiwi Bacon for their generosity and support."

It's not too late to host a Pink Ribbon Breakfast, visit www.pinkribbonbreakfast.co.nz

1. Auckland Breast Cancer Register 2000-2012, reported in March 2015



"Breast cancer sucks but I am moving forward not backwards with my life. Let's hope the money raised goes to fund more research into why and how. I am just grateful for the amazing treatment and care I have had."

Caroline's on the case



National Educator Caroline Thomas (pictured) has joined The NZBCF to drive breast cancer medical education in primary healthcare. Caroline's focus will be on GPs and Practice Nurses to provide the best possible service to women diagnosed with or at risk of breast cancer. Previously an intensive care nurse, breast cancer runs in Caroline's family so she's highly motivated both professionally and personally to boost quality of care and survivorship levels.

Learn More

Want an NZBCF educator to present to your workplace, organisation or community group?

Email breasthealth@nzbcf.org.nz or Freephone 0800 902 732

CHINESE, SAMOAN, MAORI, KOREAN +

The NZBCF have just updated their popular breast health card to include a range of languages reflecting New Zealand's increasingly diverse population. Order or download at www.nzbcf.org.nz/resources



PLEASE DONATE TO SAVE LIVES AND SUPPORT WOMEN WITH BREAST CANCER

ONLINE AT
www.nzbcf.org.nz/donate

FREE PHONE
0800 902 732

MAIL THE COUPON BELOW TO
Private Bag 99650,
Newmarket, Auckland 1149



Scan to donate

Mr Mrs Miss Ms Other

Name _____

Date of Birth ____/____/____

Address _____

Tel _____

Mob _____

Email _____

Please tick here if you don't wish to receive mail from other reputable charities.

Yes! I would like to make a donation to The New Zealand Breast Cancer Foundation

Here's my donation of \$35 \$75 \$250 Other Amount \$.....

Please make cheques payable to "The New Zealand Breast Cancer Foundation" or donate by Visa Amex MasterCard

Card No.

Name on Card _____

Signature _____ Expiry Date ____/____

All gifts over \$5 are tax deductible

Please make cheques payable to: The New Zealand Breast Cancer Foundation, Private Bag 99650, Newmarket, Auckland 1149

Please help us continue to provide our lifesaving programmes - free nationwide community education, research, public seminars, medical grants and scholarships, breast cancer patient registers, advocacy and community outreach programmes.

Breast Cream **WINS GOLD**



Last October, The NZBCF partnered with Skinfood NZ to launch a limited edition Breast Cream to encourage women to check their breasts as part of their daily beauty routine.

There are no medical ingredients; Breast Cream is just a simple, nourishing moisturiser. By applying it regularly, women get to know how their breasts normally look and feel so they're more likely to notice any changes. More than half of all breast cancers in NZ are found by women themselves between mammograms.

Advertising agency Colenso, who came up with the idea and freely provided their services, were recognized in the recent NZ Advertising Axis Awards, winning two Golds and one Silver for the Breast Cream campaign.

"We're thrilled that Colenso have been recognized for this innovative health promotion campaign," says Liz Lyons, NZBCF Communications Advisor. "Breast Cream helps promote regular self-checking which we encourage all women to do from the age of 20."

With 10,000 units sold, \$24,000 was raised for The NZBCF's research, education and breast cancer support programmes.



STEP RIGHT UP

Auckland Marathon is on 1st November.



The NZBCF has 40 spots available for runners keen on a physical and fundraising challenge. If you can commit to raising a minimum amount, a gold spot will be yours. Work teams are welcome too. Find out more at www.nzbcf.org.nz/active

Pink Star Walk in Auckland, Wellington and Christchurch.



Take a walk under the stars in October and November to raise critical money for breast cancer research. Registrations will open soon so email fundraising@nzbcf.org.nz to be added to our notification list.



Get in Touch

for information, support or to share your story.

Email: info@nzbcf.org.nz

Phone: 0800 902 732

Web: www.nzbcf.org.nz

Ask A Nurse: 0800BCNurse

f www.facebook.com/NZBreastCancerFoundation

@nzbcf on Twitter

Post: NZ Breast Cancer Foundation, PO Box 99650, Newmarket, Auckland 1149



Scan to donate

Business Partner Recognition

The New Zealand Breast Cancer Foundation is grateful for the support of the following business partners:

Corporate Partners



Pink Ribbon Platinum Partners



Pink Ribbon Gold Partners



In-kind Partners

- Fairfax Media
- Giltrap Prestige
- Bell Gully
- Soar Printing
- Colenso BBDO
- Starcom
- Post Haste
- Metrolink
- Spark Foundation
- Eftpos New Zealand