

ANNUAL REPORT 2021









Together we're stronger
Tangata tū pakari tonu



## Chairperson's Report

We've had another challenging year in which our lives and activities have been hugely disrupted by Covid and related restrictions. Online platforms have been vital in reaching out, maintaining connections with each other and continuing our work. The rare opportunities to meet and collaborate in person have been precious.

A big concern as Covid cases begin to rise, is how our health system will be able to provide timely cancer services. The BreastScreen Aotearoa (BSA) screening programme was halted at Alert Level 4 and is slowed during Levels 3 and 2. BCAC fully supports the Breast Cancer Foundation's (BCF) call to find the 133 women who have undetected breast cancer as a result of these delays. BCF's petition calls for the Government to: provide the funding and resources to process the backlog within six months; ensure breast screening continues during all lockdown levels; restore and extend the BSA programme to the 70% agreed target for ages 45 – 69 and extend coverage to 70-74 years; add breast screening participation as a measured indicator in our health system. Please visit BCAC's or BCF's website to sign the petition.

We know that many other cancer procedures have also been delayed by Covid, including diagnostic scans, surgery and many other treatment services. Urgent action is needed to provide the resources to restore cancer services to allow the best outcomes for those affected. BCAC has collaborated with other cancer patient groups to promote the New Normal Same Cancer campaign to encourage everyone to treat cancer with the urgency it deserves. While responsibility for ensuring our health system functions effectively clearly rests with the Government and the Ministry of Health there is much we can do as individuals to protect ourselves. Vaccination is absolutely top of the list. Please protect yourself and your whānau by becoming fully vaccinated. Those of us receiving cancer treatments that compromise our immune systems, such as chemotherapy, are now eligible for extra protection through a third vaccination. Talk to your specialist or GP about this. Third doses can be given eight weeks after the second shot with a doctor's prescription. If you've had a mammogram, diagnostic test, scan or cancer treatment delayed, please do everything you can to rebook and get medical attention as soon as possible. Meanwhile, mask up and stay safe!

The biggest highlight for me this year was the time I spent with an amazing group of Metavivors, filming more of our *Gifts to the Future He Koha ā Mua* videos. Those warm February days were filled with laughter and positivity as these lovely, articulate women shared the stories of their advanced breast cancer. They came together from around Aotearoa to pass on their experiences and wisdom as an enduring gift to others. We

will forever appreciate the generosity and courage of these delightful women. Jane Reeves, also a Metavivor, was our wonderfully empathetic and professional interviewer. Sadly, Jane passed away in September, moe mai rā e hoa. We will remember Jane with enduring aroha. The Metavivors NZ Facebook group has continued to be a fantastic peer-support zone and we're incredibly grateful to our committee member Terre Nicholson for the love, energy and wisdom she continues to pour into the group. Thanks to all the other wahine toa who contribute to the group and to Sweet Louise, the charity that provides direct support to those with advanced breast cancer.

During the year a new online group emerged that has become an excellent source of information and support for those diagnosed with breast cancer. Belinda Tran-Lawrence established the Aotearoa New Zealand Breast Cancer Community on Facebook and with Belinda's great communication skills, warmth and energy it has grown to be a welcoming and safe space to share experiences, thoughts and tips. We're delighted that the group has recently joined BCAC, further strengthening our broad coalition.

The BCAC committee and members attended many online breast cancer conferences this year. In a way it was convenient to hear the latest results and news without having to fly to another city or country, although we did miss the face-to-face networking. Clinical trials around the world have revealed some important advances in the use of innovative immunotherapies for breast cancer this year, with breakthroughs in treating both metastatic triple negative and HER2 positive breast cancers. As new treatments are shown to extend and save lives the future is full of hope that breast cancer will become a much more treatable and less deadly disease.

We look forward to a time when New Zealanders have greater opportunity to participate in clinical trials and to have faster access to modern medicines. BCAC is pleased to be involved in two related projects seeking to enhance clinical trial availability in Aotearoa, one led by the Ministry of Health and the other by University of Auckland. We are hopeful that these will lead to significant advancement to provide early access to innovative treatments for our women.

BCAC joined Patient Voice Aotearoa's Lie Down for Life events around the country to support the petition signed by over 100,000 New Zealanders to reform Pharmac and increase its budget. During the year we made a comprehensive written submission to the Pharmac Review Committee, and met with the committee both in person and online with other patient groups to discuss much needed reforms. We want to see an updated medicines funding model driven by aspiration to improve patient outcomes rather than by rationing and budgetary constraints. This should operate with greater speed and transparency and enable input from affected patients and their representatives. New Zealand should treat cancer patients with the medicines listed in international best practice guidelines rather than an outdated subset of these. We also responded to Pharmac's own consultations on its committee structures and its proposals to decline 'inactive' funding applications. We disputed the deletion of two breast cancer medicines on the decline list, noted that there are more effective modern versions of a

third medicine on that list and have written to oppose the separate decline of a fourth medicine. The positives are that Pharmac has shown more transparency in its intentions to decline medicines and is planning to increase input from its Consumer Advisory Committee. It will be vital that appointees to that committee are informed by patients needing a medicine under consideration and the groups that represent them.

We were pleased to have input into new draft guidelines from the Ministry of Health on breast reconstruction surgery. Once these are in place all breast cancer patients wherever they live in Aotearoa should be offered all the available surgical options. We certainly hope these guidelines don't suffer the fate of previous breast cancer-related guidelines that we have contributed to, which ended up gathering dust and never being implemented.

Back in March we briefed the Health Minister Andrew Little and Diana Sarfati, CEO of the Cancer Control Agency Te Aho o Te Kahu, on key issues facing the breast cancer community in Aotearoa. Input from across our member groups provided insight into the issues faced by women at the coalface of breast cancer and opportunities for improvement. We also highlighted three strategic areas that can deliver greater equity and better outcomes, namely: managing risk and better targeting screening; greater access to medicines; gene-based testing for greater precision in treatment.

I wish everyone inner strength, courage and joy as our resilience is tested in the coming months. There are many wonderful things to celebrate about our beautiful country, our diverse people and ourselves. Be gentle and loving to yourself and those around you and find pleasure in the small delights of everyday life.

Arohanui,

Libby Burgess, MNZM

Listy Buzer

**BCAC Chairperson** 



BCAC is an umbrella organisation representing more than 30 breast cancerrelated groups in New Zealand. Our role is to support, inform and represent people with breast cancer. We are committed to transforming the lives of those diagnosed with breast cancer by seeking world-class detection, treatment and care.



## Key Achievements in 2021

#### Information and resources

- Delivered more than 1250 Step by Step support packs to New Zealanders newly diagnosed with breast cancer. The COVID-19 pandemic again disrupted our efforts to distribute as many packs as we have in the past but with the vaccination programme well under way, we hope the lengthy disruptions to health services will ease.
- Provided information on breast cancer diagnosis, treatment and recovery via our website www.breastcancer.org.nz
- Delivered up-to-date breast cancer news, research results and events via our website, Facebook page and Twitter account.
- Delivered a regular e-newsletter to hundreds of registered members and others.
- Supported more than 2500 New Zealanders through BCAC's main Facebook page and more than 300 members in our Facebook group.
- Supported more than 400 New Zealanders with advanced breast cancer through the online communities Metavivors NZ and Metavivors NZ - Action.
- Responded to more than 50 queries through the BCAC website and Facebook page.

# Providing a voice for those diagnosed with breast cancer

BCAC committee members participate in a number of consumer and specialist breast cancer groups throughout New Zealand to ensure breast cancer patients are represented in the health system. We also engage in other activities and projects designed to raise the voices of those diagnosed with breast cancer.

 Following the Government's decision early in 2021 to conduct an independent review of PHARMAC, BCAC attended a patient group meeting with the PHARMAC Review Panel in July 2021.
 The purpose of the meeting was for the Panel to gain insight into the experiences of consumers and patients in relation to the funding of medicines and interactions with PHARMAC. Prior to this meeting, BCAC made a comprehensive submission to the Review Panel outlining our experiences, concerns and suggested reforms.

- In May 2021 at the Lie down for Life events held throughout New Zealand, BCAC supported the presentation of Patient Voice Aotearoa (PVA) - He Reo Tūroro o Aotearoa's petition calling for a review of PHARMAC and the medicines budget. PVA advocates for medicines and other improvements in the health system across a wide range of disease groups, including breast cancer.
- In collaboration with Metavivors NZ, Sweet Louise and the Breast Cancer Foundation NZ, BCAC produced 16 videos for the Gifts to the Future, He Koha ā Mua Legacy Project for those with advanced breast cancer. These videos enabled a number of New Zealanders with advanced breast cancer to create video legacies recording moments, memories, messages and insights they wanted to share. The videos are a hugely valuable resource for others facing a similar diagnosis.
- BCAC provides consumer representation on the Breast Special Interest Group (BSIG) of breast cancer specialists, with BCAC Chair Libby Burgess, Secretary Fay Sowerby and Treasurer Louise Malone all attending BSIG meetings this year.
- BCAC Deputy Chair Emma Crowley is Chair of the Consumer Advisory Panel of Cancer Trials New Zealand.
- Libby is a member of the NZ Cancer Control Agency's Te Aho o Te Kahu Consumer Reference Group, He Ara Tangata.
- Fay is a member of the Breast Cancer Trials (BCT) Fundraising and Communications Committee.
- Fay and Libby are consumer representatives on the New Zealand Familial Breast and Ovarian Cancer (NZFBOC) Group.
- Libby, Emma, Louise, Fay, Lynda Ames and Rowena Mortimer are members of Breast Cancer Trials' IMPACT Advocacy group and Libby is also an Associate Member of BCT.
- BCAC members attended the international Virtual
   Global Breast Cancer Advocacy Summit and Patient Advocacy Exchange online meetings.
- BCAC Committee member Rowena Mortimer is Chair of the Consumer Advisory Panel of the Health Quality and Safety Commission.









- BCAC is a member of the ABC Global Alliance, a European-based organization dedicated to improving and extending the lives of women and men living with advanced breast cancer worldwide. Committee members attended the virtual Advanced Breast Cancer 6th International Consensus Conference (ABC6).
- BCAC supported many women as they negotiated the health system to secure timely and appropriate diagnosis, treatment and care.

# Improving access to world class treatment and care

 Early in 2021, BCAC met with Minister of Health, Hon. Andrew Little and Prof. Diana Sarfati, CEO of Te Aho o Te Kahu, the Cancer Control Agency. We presented a comprehensive briefing and identified three key issues with solutions we believe will make a big difference to the lives of New Zealanders with breast cancer and bring



- greater equity to our health system. These issues were: managing risk and better targeting screening; greater access to medicines; and gene-based testing for greater precision treatment.
- Input for this meeting from across BCAC's 30+ member groups enabled us to provide insight to the Minister and Prof. Sarfati into many coalface issues that women with breast cancer face, revealing real opportunities for improvement.
- We met separately with politicians from other political parties to deliver our briefing.
- As part of BCAC's ongoing commitment to improving access to medicines, we provided a response to PHARMAC's consultation regarding proposed changes to their consumer and clinical advisory committees.
- Following BCAC's 2018 application to PHARMAC to fund nab-paclitaxel, this was finally referred to their Cancer Treatments Subcommittee in July this year. We provided an evidence update to PHARMAC but four months later we are still awaiting an outcome of this meeting.
- BCAC made a submission to PHARMAC supporting the retention of fulvestrant as a first-line metastatic treatment and pertuzumab as a neo-adjuvant treatment after their proposal to decline funding for these medicines. Our submission also stated that while we had no comment on the decline proposal for lapatinib, two new medicines in the same class (tyrosine kinase inhibitors), namely neratinib and tucatinib, should be funded in the near future.
- BCAC Secretary Fay Sowerby met with the Clinical Directors of Breast Screen Aotearoa and the National Screening Unit to discuss information on risk management and targeted screening to improve prevention and achieve earlier diagnosis of breast cancer. This meeting followed



the distribution of a BCAC discussion document in 2020, Moving towards personalised screening in New Zealand, that recognised how we screen, when we screen, with what frequency and what is advised and reported all need renewed focus and input from those leading, managing and participating in New Zealand's screening programmes.

- Enhancing NZ Clinical Trials Project Fay is a Steering
   Committee member for the project and Libby Burgess
   and Terre Nicholson were invited to act as consumer
   representatives for the focus group. Their work includes
   feeding into the project from a consumer perspective on
   better embedding healthcare consumers in the entire clinical
   trial pathway. The initiative aims to involve consumers in trial
   design and prioritisation, then to ensure implementation of
   results and translation into practice.
- There is also work underway to develop a National Clinical
   Trials Alliance to enhance clinical trial infrastructure and participation in New

Zealand. Both Fay and Libby participate in this via a working group, attending workshops to provide feedback on how the Alliance should be shaped and the next steps towards making it happen.

- BCAC provided feedback to the Ministry of Health's consultation on Breast Reconstruction – National guidelines for best practice.
- Libby participated in The Economist's Economic
  Intelligence Unit online meeting of breast cancer
  clinicians and patient representatives across
  the Asia Pacific region to map out a pathway
  for developing patient-centred diagnosis and treatment
  pathways for early breast cancer in each country.
- A number of meetings took place with pharmaceutical companies to learn about new products coming to the market, and to encourage companies to apply for registration and funding for key breast cancer drugs in NZ, and to make these products available to patients at affordable prices prior to public funding.
- BCAC collaborated with other patient organisations to promote the New Normal Same Cancer campaign. Due to the disruption of health services during the ongoing COVID-19 pandemic, these organisations realized the growing need to remind and encourage people to contact their health professional to get checks or attend appointments to minimise delays in diagnosis and treatment of cancers.
- BCAC committee members attended conferences and meetings to remain up-to-date with the latest thinking and innovations, many of these "virtually" in the last year as conferences have been forced online due to the ongoing pandemic. These included:







- the Breast Cancer Insights conference held in Wellington
- the Annual Scientific Meeting of Breast Cancer Trials and other online BCT meetings and events
- the online inaugural New Zealand Familial
   Breast and Ovarian Cancer conference
- the New Zealand Association of Breast Cancer
   Research's Virtual NZ Breast Cancer Symposium
- o InformD webinar
- breast cancer webinars run by the European
   Organisation for Research and Treatment of Cancer
- the St Gallen Consensus Conference on Early Breast Cancer Treatment Standards
- the UK National Institute for Health and Care Excellence's new 5-year strategy launch.
- BCAC also attended the foremost international breast cancer research conference, the San Antonio Breast Cancer Symposium in December 2020, via their online programme as consumer advocates, and will do so again in December 2021.

# Improving outcomes for Māori and Pasifika women

- BCAC continued to advocate for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori, Pasifika, rural and disadvantaged women.
- Liaised with Māori and Pasifika women affected by breast cancer and related advisory groups.
- Highlighted the poorer outcomes of Māori and Pasifika women with breast cancer and identified opportunities for improvement.
- BCAC committee member Irene Kereama-Royal provided a Māori perspective and advised on matters relating to ethnic equity in NZ breast cancer care.
- BCAC welcomed Maria Marama onto the committee to strengthen our capacity in understanding and acting on ngā take Māori.











## **BCAC Committee**

#### Those serving on the BCAC committee during 2021 were:

Chair: Libby Burgess **Deputy Chair:** Emma Crowley Fay Sowerby Secretary: Treasurer: Louise Malone **Committee Members:** Rowena Mortimer

Gillian Wintrup

Lynda Ames **Greer Davis** Irene Kereama-Royal Philippa Reed Terre Nicholson Catrin Devonald Tanya Newman Maria Marama

BCAC would like to thank and acknowledge the valuable input of Irene Kereama-Royal who stepped down from the committee during the year. We have greatly valued and appreciated Irene's commitment to improving breast cancer experiences and outcomes for Māori women, her perspectives and knowledge, in particular in the areas of genomics and te ao Māori.

We have been delighted to welcome Tanya Newman and Maria Marama who joined the committee in July and October.

In addition to the wide-ranging representation already outlined earlier in this report, BCAC committee members have been involved in many other committees, conferences and meetings in 2021, all with the aim of improving breast cancer care in New Zealand.



#### Libby Burgess, Chairperson

- Consumer representative: Cancer Control Agency Te Aho o te Kahu Consumer Reference Group He Ara Tangata
- Consumer representative: Breast Special Interest Group (BSIG)
- Met with and briefed the Minister of Health, other politicians across parties and CEO of NZ's Cancer Control Agency Te Aho o Te Kahu, on key breast cancer issues and solutions
- Attended Breast Insights conference in Wellington
- IMPACT (consumer) member and associate member: Breast Cancer Trials (Australia and New Zealand). Libby participated in the BCT

- virtual Annual Scientific meeting
- Regularly corresponded with PHARMAC and responded to consultations on PHARMAC advisory committees, operations and medicines funding
- Responded to PHARMAC Review Committee consultation and met with this group in Wellington
- Attended a number of meetings with pharmaceutical companies
- Emceed at the Auckland Lie Down for Life event organised by Patient Voice Aotearoa to support their petition to increase the medicines budget and reform PHARMAC
- Attended online meetings and virtual conference of the New Zealand Familial Breast and Ovarian Cancer Group (NZFBOC)
- Met with Southern Cross Healthcare
- Attended the online 5-year strategy launch for the UK's National Institute for Health and Care Excellence
- Invited participant at the Economist's Economic Intelligence Unit Asia-Pacific meeting to develop a 'A Patient-centred framework for early breast cancer care'
- Attended an online Patient Advocacy Exchange on Biomarkers and Gene Mutations (Australia & New Zealand)
- Attended the virtual NZ Breast Cancer Symposium
- Attended ABC (Advanced Breast Cancer) Global Alliance conference
- Enrolled to attend the virtual 2021 San Antonio Breast Cancer Symposium as a consumer advocate.



#### Emma Crowley, Deputy Chairperson

- Chair of the consumer advisory panel of Cancer Trials NZ
- Consumer representative on two breast cancer trials.



#### Louise Malone. Treasurer

- Completed BCAC's funding applications and wrote reports to BCAC's funders
- Attended a number of meetings with pharmaceutical companies and politicians
- IMPACT (consumer) member and participated in the virtual Breast Cancer Trials Annual Scientific meeting
- Contributed to BCAC's submission for the PHARMAC review
- Attended Lie Down for Life event organised by Patient Voice Aotearoa
- Attended online Patient Advocacy Exchange on Biomarkers and Gene Mutations (Australia and New Zealand)
- Attended ABC (Advanced Breast Cancer) Global Alliance conference
- Enrolled to attend the virtual 2021 San Antonio Breast Cancer Symposium as a consumer advocate.













#### Fay Sowerby, Secretary

- Chair of Breast Cancer Cure, which with the Breast Cancer Research in New Zealand Partnership funds research each year.
- Member of Breast Cancer Trials (BCT) (Australia and New Zealand)
   Communication and Fundraising Committee
- Affiliate member: BCT and participated in the virtual Annual Scientific meeting
- Met with Minister of Health and the CEO of the Cancer Control Agency
   Te Aho o Te Kahu
- Provided a submission to the PHARMAC Review Committee and attended related workshops.
- Attended a number of meetings with pharmaceutical companies and PHARMAC
- Participated in several virtual BCT Question and Answer sessions
- Attended New Zealand Familial Breast and Ovarian Cancer Group (NZFBOC)
  meetings, addressed the October meeting on Risk assessment for breast
  cancer in New Zealand and chaired a session at the conference
- Attended the ABC Global Alliance Bridging the Gap meeting
- Attended the virtual NZ Breast Cancer Symposium
- Enrolled to attend the 2021 San Antonio Breast Cancer Symposium as a consumer advocate.

#### Rowena Mortimer, Committee Member

- Chair, Consumer Advisory Panel to Health Quality and Safety Commission (HQSC)
- IMPACT (consumer) member Breast Cancer Trails
- Enrolled to attend the virtual 2021 San Antonio Breast Cancer Symposium as a consumer advocate.

#### Lynda Ames, Committee Member

- IMPACT (consumer) member Breast Cancer Trials
- Attended meetings with pharmaceutical companies and PHARMAC.

#### Gillian Wintrup, Committee Member

• Provides a voice for those with advanced breast cancer.

#### Greer Davis, Committee Member

- Member: BCS Young Women's Support Group
- Provides a voice for young women with cancer.

#### Irene Kereama-Royal, Committee Member

- Advocates for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori, Pasifika and rural women.
- Expertise in Māori genomics.





#### Philippa Reed, Committee Member

- Partnership Manager of BCAC member group, CanTeen Aotearoa
- Contributed to BCAC submissions to PHARMAC and various consultations.

#### Terre Nicholson, Committee Member

- Co-ordinates both Metavivors NZ and the Metavivors NZ Action Facebook groups
- Participated in the patient group meeting for the PHARMAC Review Panel
- Attended meetings with pharmaceutical companies
- Participated as a consumer representative in the Enhancing NZ Clinical Trials Consumer Focus Group
- Co-ordinated Metavivors NZ actions in relation to medicines access and liaised with Patient Voice Aotearoa
- Attended and coordinated Hamilton Lie Down for Life event organised by Patient Voice Aotearoa
- With BCAC's support, assisted Metavivors to obtain better medical outcomes.



#### Catrin Devonald, Committee Member

- Chief Executive of Sweet Louise
- Attended BCAC's meeting with the Minister of Health and the Te Aho O Te Kahu CEO
- Attended meetings with pharmaceutical companies
- Supported the submission to the PHARMAC Review Panel and attended the online workshop
- Sweet Louise was represented at the 16 Te Aho O Te Kahu Community Hui around the country
- Sweet Louise is a member of Advanced Breast Cancer Alliance and was showcased as best practice for services to ABC patients.



### Tanya Newman, Committee Member

- Joined the BCAC committee in July 2021
- Has an interest in wellbeing and psychosocial support
- Presented at the virtual Breast Cancer Foundation's Nurses' Day in November 2021.



#### Maria Marama, Committee Member

- Joined the BCAC committee in October 2021.
- Provides a Māori perspective and advice on cultural responsiveness
- Working to overcome inequities for Māori women
- Advocates for removing barriers and improving access to breast cancer diagnosis, treatments and reconstruction options for Māori
- Background in health and disability advocacy.

## Step by Step - Feedback in 2021



#### **PATIENTS**

"Thank you for the pack you sent out - I've read the book and started filling in the diary and journal. The diary will be really awesome - having everything all in one place."

"I think it's great - super informative and a big help for obtaining all information - it's a daunting diagnosis!"

"I have found the support from BCAC and BCF invaluable. The support pack was very helpful, particularly the prompt to journal the journey."

"Amazing - it has helped me understand so much."

"That Step by Step pack is brilliant, was so helpful...it really helped me through the process. I thought at the time, wow I bet so many people have poured their experiences and skills into developing the resources, ...it's created a really valuable kit. So appreciative for it."

"These books are amazing, I used them extensively during my treatment over the last year, and reading back now is a reminder of what I went through from diagnosis to surgery, chemo and 17 rounds of Herceptin. Brilliant idea, thanks so much."

#### BREAST CARE NURSES AND ONCOLOGY SUPPORT TEAMS

"I just love the Step by Step support pack, actually... it's excellent!" Community support worker with Māori Health Service provider

"Could we please have some more of your amazing support packs. The patients love them."

Specialist breast nurse

"Our patients really appreciate Step by Step. Easy to read and the diagrams help us to explain difficult concepts." Breast cancer nurse



## Supporters

Despite the ongoing challenges of Covid-19, BCAC has once again received generous and kind support from a number of organisations and individuals in 2021.

BCAC's relationship with The Good Registry, an organisation that helps people to give charitable donations as gifts, has continued to grow this year. We have been very grateful for the regular donations we have received from the wonderful people of The Good Registry and their 'givers'. We were especially chuffed to be awarded a share of the value of unredeemed corporate vouchers from The Good Registry this year.

Two organisations that have supported us for a number of years continued to do so this year. Health and beauty company, LeRêve (NZ) Ltd, once again made a generous donation and Storage King NZ continued to provide free storage for our Step by Step support packs.

As in previous years, a Lottery Community grant provided vital funding so that BCAC could continue to distribute **Step by Step** support packs to those newly diagnosed with breast cancer and maintain our online presence via our website, e-newsletters, and our Facebook peer support networks.

BCAC was very grateful to receive educational grants from Pfizer which allowed us to continue to learn from and participate in national and international breast cancer research meetings and



patient advocate forums. A Pfizer grant also enabled BCAC to produce a set of patient videos, Gifts to the Future, He Koha ā Mua, in which women with advanced breast cancer could leave a legacy for whānau as well as offering valuable perspectives, tips and messages for others facing a similar diagnosis. BCAC is very grateful to the late Jane Reeves, a Metavivor who interviewed video participants and to Elisa Wijohn, who set up a Givealittle page and raised funds so that more videos can be made to add to the ethnic diversity reflected in the videos.

As always, we have been touched and extremely grateful for donations received throughout the year from members of the public.

Finally, we would like to acknowledge the generosity of Carolina at Dot Design who supports BCAC with her wonderful design work for our Annual Report.

BCAC thanks all these organisations and individuals who have supported us this year and made our work and achievements for New Zealanders possible.



# **BCAC Member Groups**

BCAC is proud to work closely with all our members from the community to improve detection, care and treatment for all New Zealanders with breast cancer. Along with many individual members, BCAC is made up of more than 30 breast cancer related groups.

Age Concern

Alleviate

Aotearoa NZ Breast Cancer Community

Ascot Radiology Pink Dragons

Boobops Dragon Boat Team

**Breast Cancer Action Trust** 

Breast Cancer Foundation New Zealand

**Breast Cancer Cure** 

Breast Cancer Support Inc

**Breast Cancer Support Northland Trust** 

Breast Cancer Support Service Tauranga Trust

Busting with Life

CanTeen Aotearoa

Hope Emerges

Horowhenua Pink Ladies BCS Group

Kenzie's Gift

Life 2.0

Look Good Feel Better

Lymphoedema Support Network

Mamazon Club

Metavivors NZ

Pinc Cancer Rehabilitation Program

Rotorua Breast Cancer Trust

Shocking Pink

Support Crew

**Sweet Louise** 

Taranaki Dragons

Te Ha o Te Oranga o Ngati Whatua

Terrier Race Against Time

The Gift of Knowledge

Waikato Breast Cancer Research Trust

Waikato Treasure Chests

Well Women and Family Trust





























































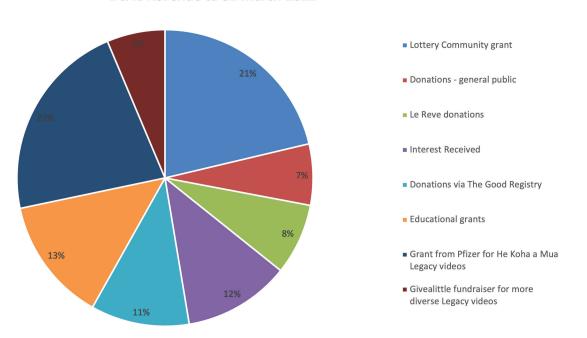




# Financials

BCAC Revenue 2020/21	
Funding Source	Amount (\$)
Lottery Community grant	\$9,710
Donations - general public	\$3,041
Le Reve donations	\$3,540
Interest Received	\$5,308
Donations via The Good Registry	\$4,910
Educational grants	\$6,184
Grant from Pfizer for He Koha a Mua Legacy videos	\$10,000
Givealittle fundraiser for more diverse Legacy videos	\$2,900
Total Income	\$45,593

#### BCAC Revenue to 31 March 2021



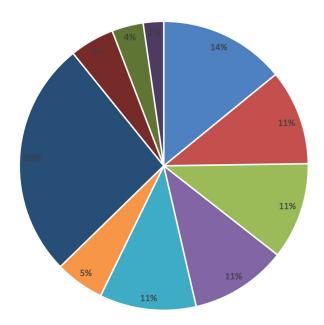


# **Financials**

## BCAC Expenses 2020/21

Expenses	Amount (\$)
Providing online information and support	\$4,871
Step by Step storage and distribution	\$3,688
Admin support for volunteers engaging with health	
providers and decision-makers	\$3,736
Admin support for volunteers providing a public voice for those with BC	\$3,736
Distributing e newsletter to member groups; answering queries	\$3,736
Attending meetings, hearings (members' expenses)	\$1,900
He Koha a Mua Legacy video production costs	\$9,157
Audit and bank fees	\$1,726
Office expenses	\$1,216
Other expenditure (DIA fee, flowers, food for meetings etc.)	\$792
Total Expenses	\$34,558

#### BCAC Expenditure to 31 March 2021



- Providing online information and support
- Step by Step storage and distribution
- Admin support for volunteers engaging with health providers and decision-makers
- Admin support for volunteers providing a public voice for those with
- Distributing e newsletter to member groups; answering queries
- Attending meetings, hearings (members' expenses)
- He Koha a Mua Legacy video production costs
- Audit and bank fees
- Office expenses
- Other expenditure (DIA fee, flowers, food for meetings etc.)



## Plans for 2022

### FOR 2022, OUR ACTIVITIES WILL INCLUDE:

To make world class detection, treatment and care accessible to all affected by breast cancer in New Zealand

- Continue engagement with decision makers at all levels. Liaise with Ministers, MPs, the Cancer Control Agency Te Aho o Te Kahu and the Ministry of Health to advocate for improved breast cancer screening, precision diagnosis and treatment and supportive care to improve outcomes and equity.
- Raise awareness of new and emerging medicines and the need for increased funding to enable broader and earlier access to treatments that will improve quality and length of life.
- Meet with PHARMAC to champion access to effective and innovative medicines.
- Meet with pharmaceutical companies and encourage them to register their innovative medicines in New Zealand, offer them at affordable prices and free of charge to patients when funding is imminent.
- Review the performance of the Cancer Control Agency Te Aho o Te Kahu and provide feedback and advice where appropriate.
- Consult, engage with, seek advice from and, when appropriate, represent Māori and Pasifika women on breast issues and advocate for actions needed to increase access to services and improve breast cancer experiences and outcomes.
- Increase education and knowledge of breast cancer, treatments, supportive care and emerging clinical trial results by attending and promoting local and international expert meetings and conferences.
- Continue to strengthen networking and collaboration among groups and individuals.

To provide information and support to empower those with breast cancer to make informed choices about their treatment and care

- Widely distribute our updated 4th edition of Step by Step to women newly diagnosed with breast cancer.
- Provide information and support for those with early and advanced breast cancer.

- Progress our investigations into the need for Māori-specific resources related to the **Step by Step** support pack.
- Provide up to date information via our website about breast cancer and our advocacy work.
- Communicate with the breast cancer community via our Facebook page and Twitter.
- Continue to support the Metavivors NZ and Metavivors NZ Action Facebook groups and members.
- Distribute news and information via our e-newsletter to hundreds of subscribers.
- Respond to requests for information and support.

### To provide a unified evidence-based voice for New Zealanders who have experienced breast cancer

- Raise awareness of advanced breast cancer and the needs of people whose disease is terminal.
- Participate in a wide range of local, regional and national breast cancer-related working groups, committees and organisations.
- Respond to consultation opportunities relating to breast cancer.
- Advocate for timely access to world-class breast care, including diagnostics, treatments and supportive care in New Zealand.
- Promote the uptake of precision tests to ensure acccurate diagnosis and appropriately targeted treatment.
- Support and promote initiatives enabling the early detection of breast cancer such as mammographic screening, breast density reporting and breast awareness by meeting regularly with BreastScreen Aotearoa to encourage continual progress with the National Screening programme, including broadening the eligible age band.

#### To support the activities of BCAC through promotion and fundraising

- Apply for grants from charitable trusts.
- Approach businesses for funding to support specific projects and activities.
- Welcome public donations via our website and newsletters.











Breast Cancer Aotearoa Coalition PO Box 90224, Victoria St West Auckland 1142, New Zealand

www.breastcancer.org.nz