



Breast Cancer Network Australia • Annual Review 2011

CONNECTION

**Breast Cancer Network Australia informs, empowers, represents and links together people affected by breast cancer.**

**Inform**

We provide quality, up-to-date information about breast cancer, its treatment and services.

**Empower**

We empower women to have a voice in their own health care and to play an active role in improving breast cancer treatment, care and services.

**Represent**

We ensure women's voices are heard by policy makers, health providers and planners through our program, policy and advocacy work, and that we are at the table wherever a decision is made about breast cancer.

**Link together**

We bring together those who have themselves experienced breast cancer and link individuals and groups sharing similar issues and experiences.

**OUR VISION**

All Australians diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible.



We are represented by the Pink Lady silhouette, symbolic of our focus on the woman diagnosed with breast cancer and all those around her.

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## OUR HIGHLIGHTS IN 2011

### MEMBERS

- More than 64,000 members
- 240 Community Liaisons
- 308 Member Groups (including Associate Member Groups)

### SERVICES

- 11,791 *My Journey Kits* distributed to women newly diagnosed with breast cancer
- More than 6000 copies of the new *Breast Cancer and Sexual Wellbeing* booklet distributed
- 'Strengthen Your Recovery' Pilates DVD developed for the *My Care Kit*
- 792 *Hope & Hurdles Packs* distributed to women with secondary breast cancer

- More than 2000 attendees at 10 information forums across Australia
- 280 key BCNA members attended the National Summit in Melbourne
- More than 11,000 *My Care Kits* distributed to women who had recently had surgery for breast cancer
- Launched Local Services Directory
- Online growth – 210,000 visits and one million page views of the website; more than 5000 online network members

### VOICE

- More than 3000 women involved in research projects
- 80 Consumer Representatives involved in projects and committees
- Sexual wellbeing research and collaboration
- Advocated for reductions in the out-of-pocket costs for public patients receiving chemotherapy in NSW
- Participated in campaigns to maintain independent process for the Pharmaceutical Benefits Scheme (PBS) and funding for medical research

### RELATIONSHIPS

- Strengthened long-term relationships with our key sponsors and supporters
- Developed new partnerships
- Renewed the funding agreement with Cancer Australia under the *Supporting Women in Rural Areas Diagnosed with Breast Cancer* Program
- Regular meetings with national breast cancer organisations
- Celebrated 11 years of partnership with Bakers Delight, our Major Partner

### PROFILE

- Celebrated Raelene Boyle's 60th, with more than 1000 guests
- Highlighted the needs of partners at an event at The Lodge
- 198 *Mini-Fields of Women* held around Australia
- More than 1000 stories across print, tv, online and radio media
- Inaugural Pink Lady luncheon held in Melbourne in October during Breast Cancer Awareness Month

## Letter from the Chair



Lyn Swinburne  
BCNA Founder

Breast Cancer Network Australia (BCNA) is a true network. Since 1998 we have been bringing people together. We support women, share knowledge and information, connect businesses and communities, influence government and health agendas, and unite people in a common cause.

Our organisation has strong, varied and enduring circles of influence; and at the centre of all of these circles are women affected by breast cancer. While no two women will have had the same experience with breast cancer, it is the similarities – not the differences – that bond our network together so strongly.

With more than 64,000 members, we are privileged to gain incredible insights into the experiences and needs of women with breast cancer. We understand that a breast cancer diagnosis can make women feel isolated and we work tirelessly to make sure women do not feel alone by providing them with a range of opportunities to connect with us and with each other.

We achieve this through hosting face-to-face events, providing online support and distributing free, comprehensive and practical information.

This year BCNA's founding CEO, Lyn Swinburne, retired from the role, after giving her all to BCNA for 13 years. One of Lyn's greatest strengths has been her ability to bring together people from all walks of life. Her legacy is a national organisation with a strong foundation.

On behalf of the Board, the team at BCNA and all of the women, I thank Lyn for everything she achieved as CEO and founder.

In November, the appointment of our new CEO, Maxine Morand, marked a new chapter for BCNA. Maxine is a well-respected advocate for women, with extensive experience in the community and health sectors and in government, and is renowned for her collaborative approach and focus on building strong relationships. Maxine was diagnosed with breast cancer earlier this year, so she understands what many women and their families have been through.

Ultimately BCNA's success, strength and effectiveness are the result of the efforts and hard work of many wonderful individuals. We look forward to building on BCNA's achievements and continuing our focus on providing quality information and support for those personally affected by breast cancer.

Marg O'Donnell  
Chair

## Letter from the CEO

I very clearly remember the *Field of Women* on the grounds of the MCG in 2010. I was an invited guest of BCNA in my then-role as Victorian Minister for Women's Affairs and Minister for Children, and I stood alongside a good friend who was a breast cancer survivor. It was an incredibly uplifting and positive experience.

Little did I know then that just a year later I would be diagnosed with breast cancer and simultaneously approached about the role of new CEO of BCNA. I was just one of more than 14,000 women diagnosed in 2011. Fortunately my treatment went well and, when I finished radiotherapy towards the end of 2011, I felt I could take on the challenge of the role of CEO with a personal understanding of breast cancer that would both inform and benefit the membership.

Taking over from founder and CEO Lyn Swinburne, I knew I was accepting responsibility for an extraordinary organisation with a substantial reputation and impressive list of achievements. The organisation is full of passionate, caring people who really connect with the mission and goals of BCNA – from our Board, staff and volunteers through to our key sponsors, supporters and the general public – working together to ensure BCNA's ongoing success.

The needs of women with breast cancer can be as complex as the disease itself. After a diagnosis of breast cancer, women have a great need to understand the disease. BCNA has been very successful in identifying what is important to women with breast cancer and what sort of information and support is needed at different stages of treatment and recovery.

The complex nature of breast cancer and the diversity of Australians affected means that BCNA must continue to adapt. We must improve our resources and our programs to meet the diverse needs of Australian women diagnosed and living with breast cancer.

The great success of treatments and improved survival contributes to a growing number of women living in our community who have had an experience of breast cancer and need ongoing treatment and management. There is also an increasing number of women living with secondary or advanced breast cancer who need further support. Face-to-face support at information forums, exploring new support mechanisms and tailored information for Australia's diverse population will be priorities for BCNA in the year ahead.

My aim is to continue the great work of BCNA and to take the organisation into a new phase through our growing membership and partnerships with our supporters.

Hon. Maxine Morand  
CEO



**Marg O'Donnell  
(Chair)**

Marg is a qualified social worker who has spent much of her career with the Queensland Public Service, including six years as Director General of three state government departments. She was also the Inaugural Legal Ombudsman in Victoria. Marg currently works as a mediator, mentor and consultant, and is Chair of the Griffith University Law School Visiting Committee. Marg was diagnosed with breast cancer in 2003.



**Andrew Barling**

Andrew is a surgeon working in both rural Victoria and metropolitan Melbourne. He is a member of the Clinical Governance Committee of the Loddon Mallee Integrated Cancer Service and also lectures at Melbourne and Monash clinical schools. In 2000, he established the Otis Foundation, which provides free rural respite for women with breast cancer. Andrew lost his first wife, Judy Burley, to breast cancer in 2000.



**Fran Boyle, AM**

Fran is a medical oncologist and Associate Professor at the Mater Hospital in North Sydney, where she is involved in breast cancer treatment and research. She is also the Medical Director of the Pam McLean Cancer Communications Centre at the University of Sydney. Fran is a member of the Board of the Australia New Zealand Breast Cancer Trials Group and is also vice-chair of its Scientific Advisory Committee. In 2002, Fran was awarded the AMA Women's Health Award for her contributions to breast cancer research, policy, education and care. In 2008 she was appointed as a member of the Order of Australia.



**Raelene Boyle, AM MBE**

As a track and field athlete, Raelene was selected to represent Australia at four Olympic Games, attending three of them. She has won three Olympic Silver Medals, seven Commonwealth Gold Medals and two Commonwealth Silver Medals. In 2007, she was made a Member of the Order of Australia in recognition of her work with cancer organisations, particularly Breast Cancer Network Australia. Raelene is one of the National Trust's 100 Living Treasures, a member of the Sport Australia Hall of Fame and the Australian Track and Field Hall of Fame. Raelene was diagnosed with breast cancer in 1996 and ovarian cancer in 2000 and 2001.



**Terry Bracks  
(Deputy Chair)**

Terry is the Founding Chair of Western Chances, a scholarship program for young people in the western suburbs of Melbourne, and a former board member of the Australian Children's Television Foundation. She is also a trustee of the Victorian Arts Centre Trust. She received a Centenary Medal in 2001, an Honorary Doctorate from Victoria University in 2008, and a Victoria Police Citizen's Commendation Award in 2009. She was AFL Football Woman of the Year in 2007 and was inducted into the Victorian Women's Honour Roll in 2011. Terry is patron of Heide Gallery, and the Williamstown Literary Festival.



**Mike Happell**

Mike is a partner of PricewaterhouseCoopers, and has held numerous leadership roles with them since 1993. He is currently the National Energy and Resources Industry Leader. He has been recognised in the International Tax Review, where he was named in the 'Top Ten Tax Advisors in Australia' and 'Leading Australian Transfer Pricing Advisor'. He was also named in 'Best of the Best' Global Tax Advisors in *Euromoney* magazine. Mike is a member of the Councils of Lauriston Girls School and Scotch College in Melbourne, and is a committee member of the Melbourne Cricket Club. Mike has three daughters and is married to Tatty who is a breast cancer survivor.



**Karen Hayes  
(Deputy Chair)**

Karen has extensive business management, strategic consulting and human resources experience in Australasia, Canada, the United States and many European countries, primarily in the financial services and professional services industries. Appointed to the role of Chief Executive Officer for Guide Dogs Victoria in November 2011, Karen previously held the position of Director, Corporate Engagement & Human Capital with UXC Limited and CEO of Planpower, a leading provider of project management and training services. She is also a member of the Board of the Melbourne Football Club. Karen was diagnosed with breast cancer in 1996.



**Andrea Hull, AO**

Andrea has been a CEO and senior executive in government and not-for-profit organisations for more than 30 years, most recently as CEO of the Victorian College of the Arts. She has a background in cultural policy and programs and arts education at international, national and state levels. She is currently the Deputy Chair of the National Museum of Australia, and a Board member of the Florey Neuroscience Institute, the Melbourne Prize and the Abbotsford Convent Foundation. She has a BA Dip Ed (University of Sydney) and an MBA (Melbourne Business School, University of Melbourne) and is Professor Emeritus at the University of Melbourne. She was diagnosed with breast cancer in 2006.



**Christobel Saunders**

Christobel trained as a doctor in the United Kingdom, and was a consultant surgeon and senior lecturer at University College London Hospitals before moving to WA in 2000. Since November 2002 Christobel has been Professor of Surgical Oncology at the School of Surgery, University of Western Australia. Professor Saunders is a member of numerous committees, including the Advisory Council for Cancer Australia. She is also well known for her contributions to breast cancer research, education and for advocacy on behalf of women with breast cancer.



**Gabrielle Trainor**

A former lawyer, journalist, public sector executive and consultant, Gabrielle has been a non-executive director and chair of a large range of public, private and not-for-profit entities for 20 years. She was a founding partner of John Connolly & Partners, a specialist issues management firm which advises top 20 ASX listed companies. She is a director of organisations including the Barangaroo Delivery Authority, the GWS Giants Australian Football Club and the Whitlam Institute. She is an Honorary Associate of the Graduate School of Government at the University of Sydney.

**OUR BOARD**

**OUR PATRON**

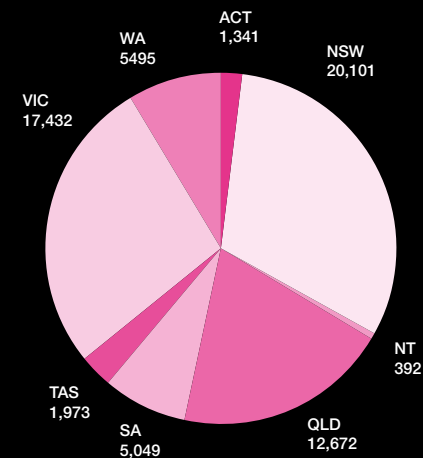
Her Excellency  
Ms Quentin Bryce AC,  
Governor-General of the  
Commonwealth  
of Australia

## OUR MEMBERS



A shared experience of breast cancer connects our membership across Australia. More than 95 per cent of our members are women who have had a breast cancer diagnosis. The remaining members are people who have been affected by breast cancer through the experience of a family member or friend.

With approximately 14,000 women diagnosed with breast cancer each year, our membership continues to increase. At the end of 2011 we had more than 64,000 members across Australia.



## Connecting with communities

Over the years Breast Cancer Network Australia (BCNA) has developed innovative community programs that develop strong relationships with key groups and women around Australia and extend our reach in communities, especially those in regional, rural and remote areas. Through our Member Groups and Community Liaisons we are able to offer tangible support, and provide up-to-date and relevant information to those who need it most.

Member Groups help to spread the word about our resources and services to local communities.

### Member Groups

From Broken Hill to Broome, from Perth to Pennant Hills, from Tumut to Townsville and everywhere in between, BCNA Member Groups support communities, inform their members, and come together during challenging times. They connect women into our network of support, and help us reach women and families affected by breast cancer in communities across Australia.

Member Groups help to spread the word about our resources and services to local communities, participate in our programs and events, and raise awareness about breast cancer and the work of BCNA.

In return we provide them with quality, up-to-date information about breast cancer. We link them to other support groups, health professionals and individuals affected by breast cancer and support them in practical ways, such as promoting their group, providing public liability insurance and hosting a summit every two years.

Their support at a local level is invaluable and enables BCNA to connect with women.

In 2011, we had 35 new Member Groups register with BCNA, taking our total to 288.

### Groups by state

State	2008	2009	2010	2011
NSW	61	74	85	87
VIC	60	71	77	79
QLD	23	32	39	54
WA	5	14	17	20
SA	21	28	28	31
TAS	5	6	11	11
ACT	3	4	2	2
NT	3	3	4	4
<b>Total</b>	<b>181</b>	<b>232</b>	<b>263</b>	<b>288*</b>

\* 2011: 35 new groups / 10 groups closed

### Member Groups across Australia

The number of groups outside major cities highlights the importance of peer support for women in rural areas

Location	2008	2009	2010	2011
Major Cities	64	82	83	93
Inner Regional	61	78	91	98
Outer Regional	45	57	67	74
Remote	10	12	18	18
Very Remote	1	3	4	5

*Community Liaisons*

BCNA is often approached by individuals who have experienced breast cancer and who want to know how they can give back to their local community. Our Community Liaison program, established in 2007, helps to give these women the skills and training they need to connect with others in their communities. With our help they gain a better understanding of breast cancer, its treatment and impact, and the confidence to talk about their personal breast cancer story.

Community Liaisons are volunteers, BCNA representatives and are our personal connection to communities all across the country. They build awareness and increase support for people affected by breast cancer. Community Liaisons represent BCNA in their local communities and speak to community groups and the media. They also act as a voice for women, clearly articulating which issues affect the women in their area, and providing us with an invaluable grassroots connection to the community.

By the end of 2011, we had 240 Community Liaisons working around Australia. This number has doubled since the end of 2008.

Rural and regional Community Liaisons comprised 44 per cent of the group. We have trained 49 women over a two-year period, including three Aboriginal Community Liaisons.

State	2008	2009	2010	2011
NSW	32	40	47	58
VIC	44	57	73	81
QLD	20	25	35	37
WA	5	9	15	19
SA	7	13	17	19
TAS	8	8	11	11
ACT	9	10	12	12
NT	2	2	3	3
<b>Total</b>	<b>127</b>	<b>164</b>	<b>213</b>	<b>240</b>

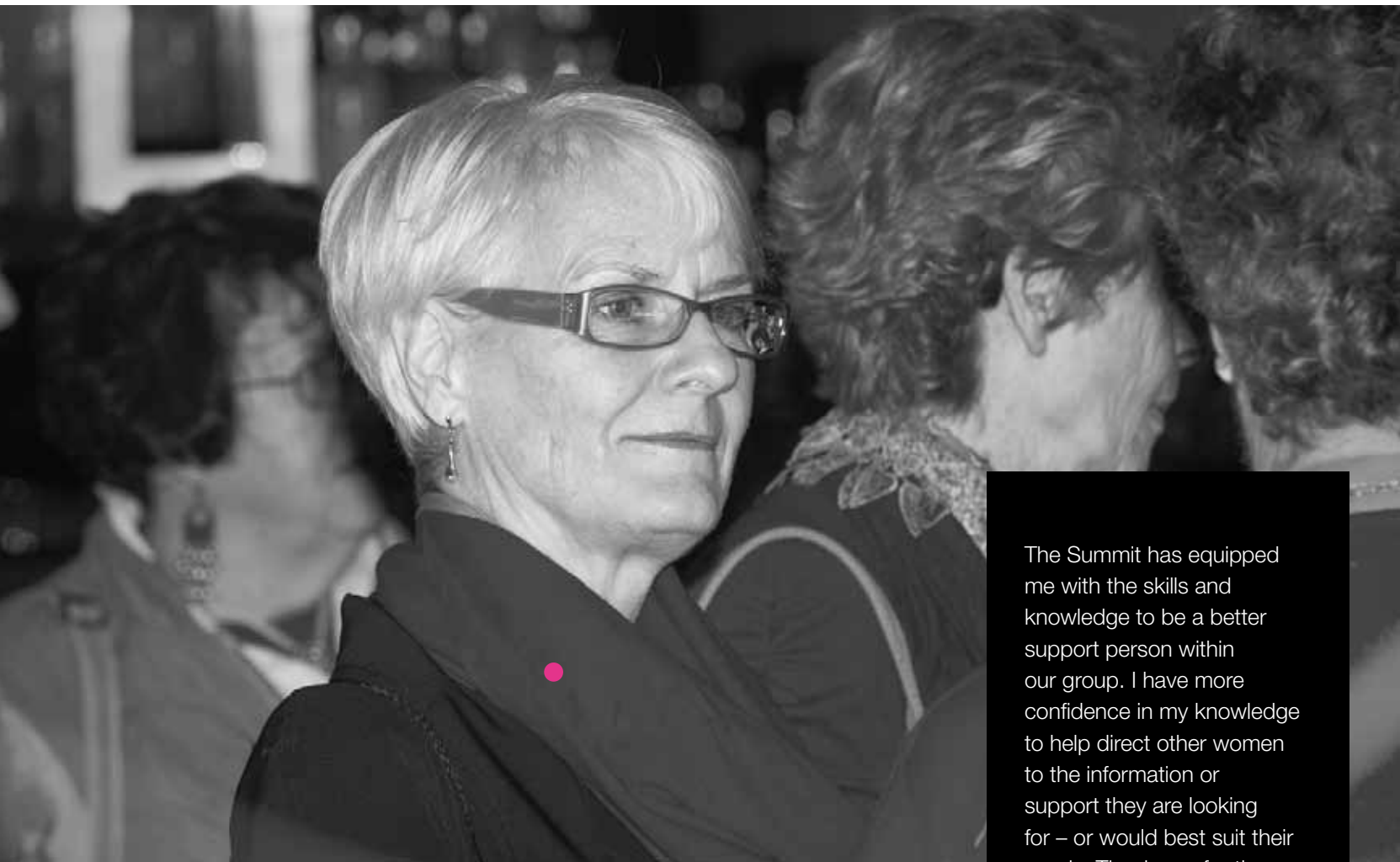


Thank you all for the invigorating and inspiring days in Melbourne. Also, my deep thanks for putting me in touch with so many dedicated and caring women throughout Australia.  
– Vivienne

*Before the training I wanted to do something in the community, but I didn't know how to go about it. Now I have the knowledge and information to get awareness and support out there.*

– BCNA Community Liaison

**By the end of 2011, we had 240 Community Liaisons working around Australia.**



The Summit has equipped me with the skills and knowledge to be a better support person within our group. I have more confidence in my knowledge to help direct other women to the information or support they are looking for – or would best suit their needs. Thank you for the opportunity to attend.

– Marg

### Connecting key women

In August 2011 we hosted a National Summit for key women and Member Groups to:

- connect and network with each other
- support them in their leadership role in their communities
- hear directly about how they need to be supported in their work
- acknowledge their contribution
- inspire them to return to their communities re-energised.

A total of 280 women attended the event in Melbourne, comprising 268 Member Group representatives, as well as individual Community Liaisons and Consumer Representatives. Of the attendees, 153 (57 per cent) came from regional, rural and remote areas. The event was made possible through funding from the Australian Government.

The Summit program featured presentations from leading women and breast cancer clinicians, as well as a series of breakout sessions and workshops on topics of interest.

These included:

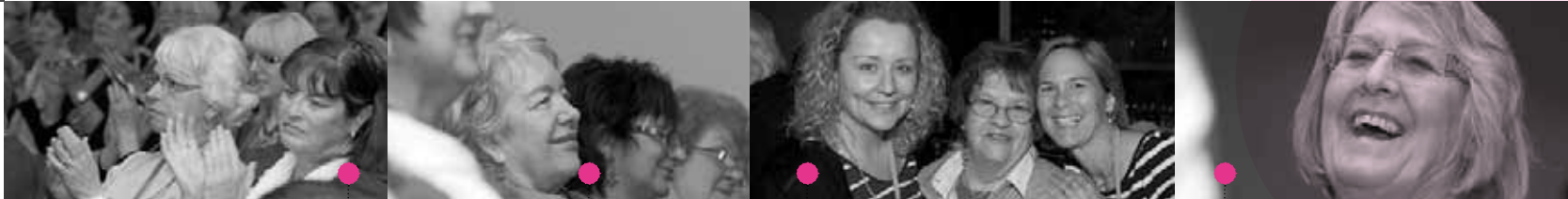
- hormonal therapies/menopause
- women’s survivorship priorities
- managing group dynamics
- caring for others when you have been there yourself
- responding to grief and loss
- secondary breast cancer
- emotional wellbeing/fear of recurrence
- genetic testing.

*The Summit has strengthened my knowledge base, offered me support and encouraged me to do even more to spread the BCNA word.*

– Jenny

*Fantastic learning and networking opportunity – very professional and empowering.*

– Peta



Women at BCNA’s National Summit



**OUR SERVICES**

We offer a diverse range of services for women, including free information, online support and face-to-face events to help inform and connect women with breast cancer. Some of these services are provided at significant milestones in a woman's breast cancer journey; others are available for women many years out from their diagnosis.



**Reaching women directly**

*The Beacon*

*The Beacon* is a free quarterly magazine that has resonated with BCNA's membership since the first issue was sent out in 1998. It offers women up-to-date information about breast cancer, events, programs and issues of importance to them. Each issue also features stories sent in from women about their experiences.

The magazine is posted out to more than 70,000 people across Australia.

*The Inside Story* is a free supplement to *The Beacon* and offers information and support to women with secondary breast cancer, and reaches around 7000 people.

*I would like to take this opportunity to thank you for the fabulous Beacon magazine. As much as it brings tears to my eyes every time I read it, it also gives me great comfort in knowing I'm not alone and how fortunate I am.*

- Nicolette

*My Care Kit*

The *My Care Kit* is provided free for women who have recently had breast cancer surgery. The kit contains a specially designed Berlei bra and soft forms. It is ordered on behalf of women through our connections with breast care nurses and other related health professionals.

A total of 11,323 *My Care Kits* were distributed during 2011, an average of 218 kits per week. This is a 15 per cent increase from the previous year. Approximately 80 per cent of women diagnosed in 2011 have received a *My Care Kit*, a significant increase from the 70 per cent reach achieved in 2010.

In 2011 we worked with Estee Lauder to produce a post-surgery exercise program using Pilates techniques. '*Strengthen your recovery*' is a DVD designed to provide women with easy-to-follow, gentle Pilates exercises and instructions to help regain strength and ease discomfort in the affected arm and chest area after recently having breast cancer surgery. The DVD has been included in the kit since December 2011.



Congratulations on producing the Pilates DVD. It is such a wonderful aid to help women have the confidence to maintain their fitness throughout the difficult period as they recover from breast cancer treatment. I will strongly recommend that my clients follow this program.

- Mary Shearer, physiotherapist



BCNA volunteer  
Marg packing  
resources



### My Journey Kit

One of our key resources, the *My Journey Kit* is an information and support pack for women newly diagnosed with breast cancer. The kit provides information and practical advice from women who have experienced breast cancer and includes a *Personal Record*, where women can record important details such as appointments, treatment and results.

In 2011 we distributed 11,791 *My Journey Kits*, an average of 227 per week, which is 4 per cent higher than the previous year.

Based on projected incidence, we estimate that the *My Journey Kit* reached 83 per cent of women diagnosed in 2011. As at the end of December 2011 this year, a total of 68,643 kits had been distributed since 2004.

The majority (75 per cent) of kits were ordered within four weeks of diagnosis, with the first 30 per cent ordered within a week. They are ordered mostly via breast care nurses who have a key role in connecting BCNA to women.

*Thank you for the prompt delivery of My Journey Kit. After reading all the information I understood my emotions and didn't feel so alone ... I now feel stronger to deal with surgery next week and the radiation that will follow.*

– Gill

**In 2011 we distributed 11,791 My Journey Kits – an average of 227 per week.**

### Hope & Hurdles Pack

*Hope & Hurdles* is a free information resource for women living with secondary breast cancer (when breast cancer has spread to other parts of the body). The pack contains booklets, brochures, magazines and CDs that offer information, support and hope for women and their families.

In July 2011, we initiated a major project to review the information needs of women with secondary breast cancer. This involved extensive input from women with secondary breast cancer and health professionals, including focus groups and an online survey, along with a review of the literature and resources available overseas, and insights from recent research conducted by BCNA.

This thorough research will improve the second edition of *Hope & Hurdles*, due for release in 2012, and ensure it reflects the needs and preferences of women with secondary breast cancer.

In 2011 a total of 792 *Hope & Hurdles* Packs were distributed, an increase of 5 per cent from 2010.

More than 4500 packs have been distributed to women since the launch in June 2007. A key goal for the second edition to be released in 2012 is to increase our reach.



*Thank you for sending me the Hope & Hurdles Pack. It was very hard for me to read at first when I was in such cloudy days. With the care of my oncology doctor and breast care nurse support I am doing okay. The pack gave me lots of help and encouragement. I am staying positive and hopefully my story one day can encourage others.*

– Jan

*BCNA member, Jo with her supporter, Kylie*

You guys are wonderful on this site. You are making me feel so much better than I did just 24 hours ago with all the positive comments and sound advice.

- Jo

I appreciate so much this website, knowing that every time I vent my frustration, all you lovely ladies on this network understand where I'm coming from and what I'm going thru.

- Monica

I think all you ladies are fantastic. I have known about the cancer for 6 weeks now and have suffered in silence, I should have posted a blog before but didn't realise how supportive everyone is!

- Sandra

## Connecting online

BCNA's website is a comprehensive resource for those wanting to learn about the activities, initiatives, support groups, programs and services we offer. It features stories written by women who have experienced breast cancer, with tips on how they coped. It also has links to other trusted websites and resources.

The online network helps women connect from anywhere in Australia and at any time of the day or night. This helps to greatly reduce the feelings of isolation that can come with a diagnosis of breast cancer.

In 2011, our online network continued to thrive, linking together women with similar experiences, regardless of location. Participation rates by network users continue to be ahead of expectations, with blog posts and comments per day significantly higher than 2010.

During 2011, there were more than 210,000 visits to the BCNA website, and more than one million page views. By the end of December 2011, the online network had more than 5000 members and 90 online groups, covering a range of special interests including groups for partners and supporters, for different diagnoses and for

different demographic groups. The biggest growth in participation through 2011 was the 55+ age group, while 42 per cent of users live in regional and rural areas.

In 2011, we launched the Local Services Directory, providing women with a way to find breast cancer-related services and support close to where they live. Directory listings, such as a sympathetic hairdresser, lymphoedema masseur or a wig supplier, are recommended by our members, and can be searched by other women using keywords or location.

We also help connect women to support groups by providing Member Groups with web pages on BCNA's website that they can update themselves. The Member Group pages had more than 32,000 visits in 2011, with the Member Group search page ranking as the 10th most visited page in the site.

**During 2011, there were more than 210,000 visits to the BCNA website, and more than one million page views.**

## Connecting rural women

We deliver free forums to women in rural and remote Australia to provide them with practical and insightful information to assist them to live well beyond breast cancer and find support in their communities. Guest speakers include leading health professionals who provide information on breast cancer and emotional wellbeing.

We also ensure a local breast care nurse, or related health professional speaks at the forums, enhancing and strengthening existing links within the community.

In 2011, more than 2000 people attended our 10 forums in regional areas and in major cities: Whyalla (SA), Wagga Wagga (NSW), Sydney (NSW), Sunshine Coast (QLD), Hobart (TAS), Newcastle (NSW), Brisbane (QLD), Coffs Harbour (NSW), Wollongong (NSW) and Adelaide (SA). The forums in Newcastle and Coffs Harbour were organised by local BCNA members in partnership with BCNA.

*BCNA member, Catherine, at a forum*



A great informative session with a group of rural people, being able to get together at an event we don't normally have access to.

- Joan

We thank the following speakers who presented at the forums throughout the year: Gabrielle Asprey, Jennifer Baker, Kellie Bilinski, Claire Blake, Dr Richard de Boer, Dr Jacquie Chirgwin, Dr Stephanie Dowrick, Sarah Franklin, Dr Jemma Gilchrist, Dr Katharine Hodgkinson, Lynda Horning, Kris Kelly, Margaret Lawton, Denise Marshall, Dr Nicole McCarthy, Margaret McNaughton, Lee Millard-Newton, Sue Munro, Dr Michelle Nottage, Cecelia Preston, Elizabeth Rose, Dr Sid Selva-Nayagam, Camille Short, Karen Sprigg, Rosalie Taggart, Assoc. Prof. Nicholas Wilcken, Lyn Williams, Michele Zilm, and BCNA Board members Assoc. Prof. Fran Boyle, Raelene Boyle and Marg O'Donnell.

BCNA works to ensure the voices of women affected by breast cancer are heard to help improve the experience of women in their treatment, care and survivorship. We achieve this through collaborating with a wide range of organisations and individuals including policy makers, health professionals, researchers, cancer organisations and government.

We gather and report on information from our members which helps inform our program, policy and advocacy work.



## Advocacy

Our strong connection with our membership gives us significant insight into the diverse needs and experiences of women affected by breast cancer. In 2011 we heard from many women that their diagnosis had a big impact on their sexual wellbeing, but that they often could not find the information or support they required. Many health professionals told us that they felt uncomfortable discussing this issue with women, and sometimes weren't sure where they could refer women for further assistance.

BCNA commissioned Professor Jane Ussher and her team from the University of Western Sydney to conduct research with women and health professionals on the impact of breast cancer on women's sexual wellbeing. Over a two-week period, 2210 BCNA members completed the survey, along with 159 health professionals.

The key themes and issues raised in the research informed the development of a comprehensive booklet on breast cancer and sexual wellbeing which was guided by an expert reference group.

The booklet, aimed at women with breast cancer, provides practical, down-to-earth information and advice on dealing with the impact of breast cancer on sexual wellbeing. The booklet also assists health professionals working with women, by helping them to raise these sensitive issues with women and provide them with practical advice. Approximately 6000 booklets were distributed to women and health professionals in 2011.

BCNA has also promoted the results of the research to women with breast cancer, as well as at numerous national medical conferences, in health professional publications, and through other mainstream media.

Throughout the year we focused on survivorship and living well after breast cancer. During 2011 we collaborated with various groups to:

- determine that waiting times for breast reconstruction were reasonable for women around the country. BCNA surveyed more than 470 women and promoted the results to other women with breast cancer and health

professionals. This has resulted in some requests for additional data from our study by clinical researchers who are keen to further investigate waiting times in their local area

- better understand women's experience of radiotherapy. BCNA surveyed over 200 women with breast cancer and found that while many women experienced burns, they were usually temporary and treatable. However, women did not always feel informed about, or prepared for, this side-effect. Many women also shared their tips for managing burns. We promoted the results nationally to women and health professionals
- advocate for improvements in the health system, to benefit women with breast cancer, including maintaining funding for medical research, maintaining independent decision-making processes for the Pharmaceutical Benefits Scheme (PBS) and advocating for reductions in the out-of-pocket costs for public patients receiving chemotherapy in NSW.



*Dr Emilee Gilbert, Prof Janet Perz,  
Prof Jane Ussher, University of  
Western Sydney*



*Presentation to medical students  
at the University of Melbourne*

## Seat at the Table program

Our *Seat at the Table* program ensures decision makers in the national and state health and related systems are connected to the experiences of consumers – women affected by breast cancer and their families. We invite, train, appoint and support women who have had breast cancer to become BCNA Consumer Representatives. Our trained Consumer Representatives participate on committees and research panels across the country and contribute informed views to benefit women affected by breast cancer.

During the year we focused on strengthening our connection with existing Consumer Representatives and training new women in the role through:

- bringing together 38 Consumer Representatives from across the country to attend our National Summit in Melbourne
- training 19 new Consumer Representatives.

By the end of the year we had 80 Consumer Representatives, with 55 Consumer Representatives appointed to various projects and activities.

Some appointments reflect the strength of long-term relationships with organisations that value consumer involvement and work closely with BCNA, for example Cancer Australia (formerly the National Breast and Ovarian Cancer Centre), Consumers Health Forum and the National Breast Cancer Foundation.

We also supported Consumer Representatives on over 30 committees throughout the year, with the majority operating at a national level. This extensive representation is invaluable to driving change and improvements for women.

## Research

### Consumer research

BCNA participates in a diverse range of collaborative research projects to ensure the research is meaningful and beneficial to women and their supporters, and that results are applied in an appropriate way and timeframe.

This year BCNA focused on the following research projects, which we selected because the results can be implemented to directly benefit women with breast cancer:

- developing a survivorship care plan project for women with breast cancer<sup>1</sup>
- bra discomfort as a barrier to exercise for women with breast cancer<sup>2</sup>
- developing an information guide on breast reconstruction for women with breast cancer<sup>1</sup>
- the support and information needs of women living with secondary breast cancer.<sup>3</sup>

### Review & Survey Group

We provide women with the opportunity to get involved in a range of research projects through our *Review & Survey Group*. This also helps connect researchers to women they are seeking for their research.

By the end of 2011, the number of women in the group was approximately 1000, an increase of 20 per cent from the previous year. Women received invitations to participate in a wide range of research studies including:

- trialing a home-based exercise program which aims to assist breast cancer survivors to participate in regular exercise
- a clinical trial that aims to improve the symptoms of 'chemobrain'
- research that aims to understand the decision-making role that family members have in cancer consultations

- an online survey about menopause issues
- how women diagnosed with cancer manage distressing emotions and feelings of control over their diagnosis.

Our ability to connect with our membership and to link them to the decision-makers will continue to help improve outcomes for women with breast cancer.

<sup>1</sup>University of Sydney

<sup>2</sup>University of Wollongong

<sup>3</sup>Peter MacCallum Cancer Centre

*I think the training has been immensely informative and has opened my eyes to the imperative role Consumer Representatives play*



Consumer Representatives  
trained in 2011

Exploring bra discomfort as  
a barrier to exercise

## OUR RELATIONSHIPS

We endeavour to form strong connections with many different organisations and individuals to help strengthen our network, raise awareness of our cause and to reach more women and more supporters.

We work closely with our 'sister' organisations – National Breast Cancer Foundation, Cancer Australia (formerly National Breast and Ovarian Cancer Centre) and the McGrath Foundation. Each organisation has its distinct focus, and we complement each other's work in our aim to achieve the best outcomes for women with breast cancer.

### Government

During 2011 the Australian Government, as part of its *Supporting Women in Rural Areas Diagnosed with Breast Cancer* program, supported three key BCNA programs. The funding was provided to improve support for women in rural and regional communities and helped us to host our regional and rural forums, and develop our website and online network. As part of the funding, 49 Community Liaisons based in rural communities have been trained over a two-year period, including three Aboriginal Community Liaisons. Funding also contributes to the development and distribution of our key resources, *My Journey Kit* and *Hope & Hurdles Pack*.

### Key partners and sponsors

We are proud of our long-term and enduring connections with key organisations that are committed to helping women affected by breast cancer.

Bakers Delight is our Major Partner and has been supporting BCNA since 2000. This partnership extends throughout Australia with more than 600 franchisees involved in our major fundraiser each year – the Pink Bun campaign. This fundraising activity also helps to raise awareness of breast cancer in local communities.

Our long-term partnership with Sussan began in 2006. The Sussan team supports BCNA in so many ways – from selling products in store with a donation made to BCNA, to providing opportunities for the public to hear about how BCNA can support breast cancer survivors. This true partnership extends our reach to women in local communities with staff in Sussan stores letting women know to contact BCNA if they or someone close to them is diagnosed with breast cancer.

Australia Post has been a valued supporter of BCNA since 2001. Our partnership ensures those diagnosed with early or secondary breast cancer receive their kits quickly so women have important information and support when they need it. Australia Post distributes the *My Journey Kit* and *Hope & Hurdles Pack* free of charge throughout Australia.

Pacific Brands/Berlei sponsors the *My Care Kit* through which it provides Berlei post-surgery bras to women who have had surgery for breast cancer. This successful program reached more than 11,000 women this year. We greatly appreciate the support and provision of bras from Berlei each year.

We would also like to thank our corporate supporters who donated to us: BHP Billiton, Dunlop Flooring, Ernst & Young Foundation, Estee Lauder, Jellis Craig, Manildra Group, NAB, Nissan Australia, Peter McInnes Pty Ltd.

The following supporters generously provided pro bono work for BCNA during the year, helping us to work more efficiently and cost-effectively: Australian Paper, Channel 9, Designgrant, Freehills, Multiwall, Naughtons Transport, Precision Forme Cutting, Starpack, Vega Press.

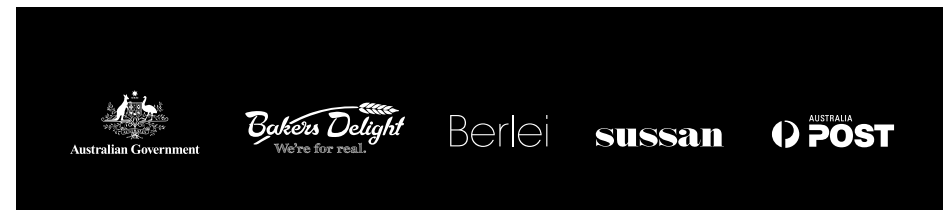
### Workplace giving

We thank the organisations which have chosen BCNA to be part of their workplace giving programs. In 2011 staff from the following organisations generously supported BCNA:

- Aviva
- BHP
- Charities Aid Foundation
- City of Boroondara
- Coles Group
- Collins Foods Group
- Macquarie Group
- Norwich
- Sussan
- Target

Australia Post staff with My Journey Kits

McGrath Foundation CEO Kylea Tink; BCNA Founder Lyn Swinburne, Prof. Lesley Fallowfield; McGrath Foundation General Manager Tracey Bevan and Dr Amanda Hordern from Cancer Council Vic at the Breast Care Nurses Conference 2011



Roger and Lesley Gillespie, Bakers Delight co-founders and CEOs



BCNA volunteers and Berlei staff with My Care Kits



BCNA member Judith  
at a Mini-Field of Women, Qld



Our *Mini-Fields of Women* are one way for local communities to pay tribute to those affected by breast cancer.

These touching events involve planting 100 Pink Lady silhouettes on which people place tags with messages of support or remembrance. During the year, BCNA provided free materials and support for 198 *Mini-Field of Women* events, featuring more than 15,000 personal tribute messages attached to silhouettes.

We are also involved in raising awareness of breast cancer and funds for BCNA through community gatherings such as *Pink Lady* events, Pink Footy & Netball Day, and various fun runs around the country, including the Sussan Women's Fun Run for which we are the sole charity partner.

This year Olympic legend and inspirational BCNA Board member Raelene Boyle generously dedicated her 60th birthday as a fundraising event for BCNA. She also celebrated 15 years of survival since being diagnosed with breast cancer in 1996.

The party, held at the Crown Palladium in July 2011, was attended by 1000 guests, including Prime Minister Julia Gillard and Victorian Premier Ted Baillieu.

Thanks to the support of BHP Billiton and donations from hundreds of companies the event was an enormous fundraising success.

A morning tea highlighting partners of women diagnosed with breast cancer was hosted at The Lodge in Canberra by Tim Mathieson. The event aimed to draw attention to the need for more support for partners. It was well attended by local BCNA members and supporters, as well as government contacts and medical organisations. Prime Minister Julia Gillard MP was a guest at the event.

We also held our inaugural Pink Lady Luncheon which brought together key supporters of BCNA. This year's event was dedicated to Lyn Swinburne as she stepped down from the role of CEO. The theme was 'Then and Now', and highlighted how few connections there once were compared with today. The event was also an opportunity to introduce and welcome our new CEO Maxine Morand.

In recognition of Lyn's contribution and BCNA's support of people affected by breast cancer, BCNA's Patron, Governor-General Quentin Bryce, also hosted a Reception at Admiralty House.

Photo: Andrew Sikorski



Scott and his partner  
Liz at The Lodge

Premier of Victoria, Ted Baillieu MP, Raelene Boyle  
and Prime Minister Julia Gillard

Kelly and Emily  
at a Mini-Field in Mornington, VIC



BCNA volunteer Angela helping out in the office

BCNA recorded a significant surplus in 2010 (1.4M), with significant fundraising activity through *Field of Women LIVE* and the Shane Crawford run, plus a generous bequest of \$500k.

The goal for 2011 was to utilise some reserves to fund expanded support for people affected by breast cancer. This is reflected in the reduction of income (20%) and corresponding increase in our investment in service provision (20%).

Our major fundraising event for 2011 was Raelene Boyle's 60th birthday party held in July. This event raised net income in excess of \$300,000 from a combination of ticket sales, silent auction items and donations.

The Australian Government has continued its financial support of the following programs:

- *My Journey Kit, Hope & Hurdles Pack*
- *Supporting Women in Rural Areas Diagnosed with Breast Cancer*. A new funding agreement was entered into at the end of 2011 which will provide \$1.242 million over three years from July 2011 to June 2014.

Our major source of income continues to be donations and community fundraising.

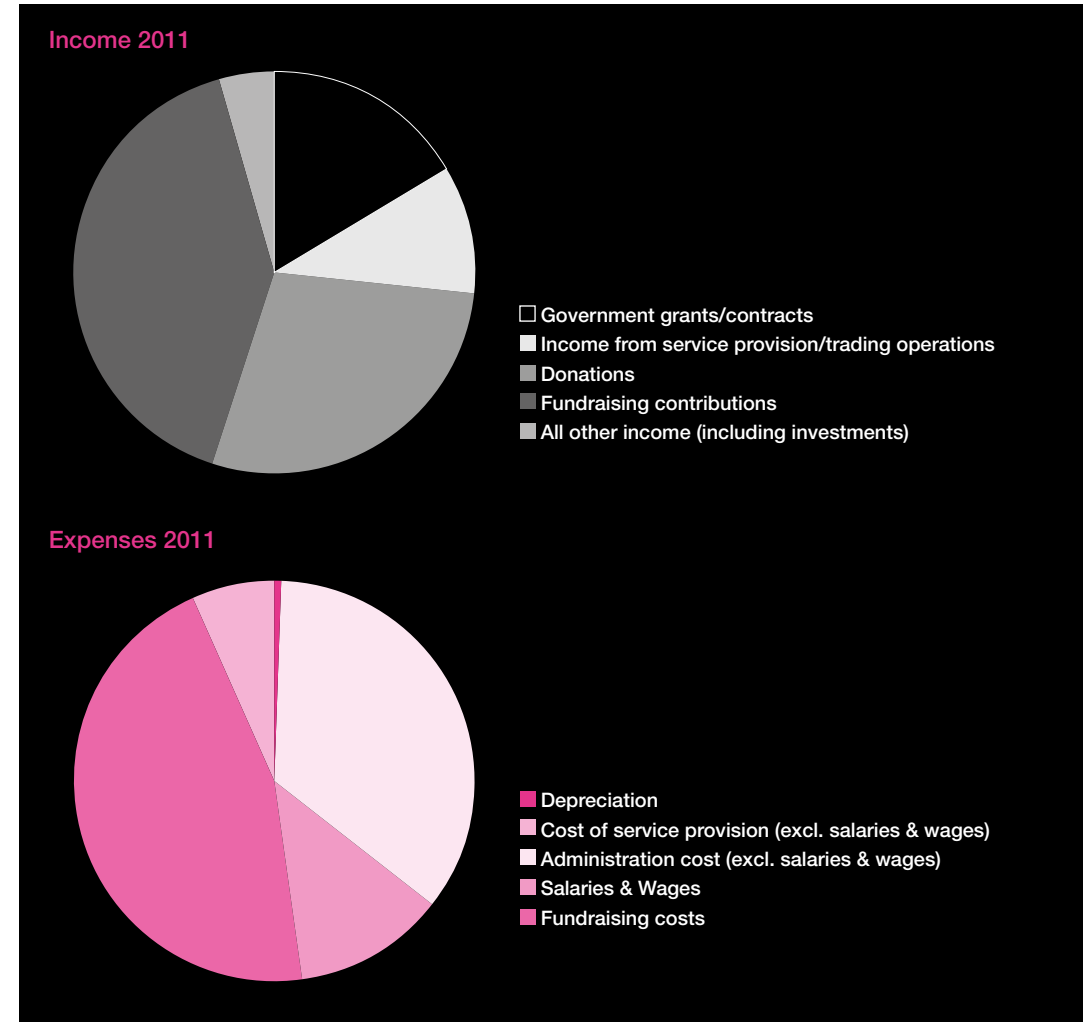
The increase in administration costs in 2012 is due to BCNA incorporating overhead costs previously covered by Bakers Delight. Up until the end of 2010, Bakers Delight generously supported BCNA with a fully equipped office, including computers, telephones and information support services. Due to the growth of our organisation, the Board felt able to take responsibility for some of those costs and have Bakers Delight support us in other ways. Bakers Delight continues to be our Major Partner and sponsor and has been very supportive during this transition phase.

**Income & Expenditure Summary**  
Year ended 31 December

Income	2011	2010
	\$000	\$000
Government grants/contracts	823	833
Income from service provision/trading operations	500	780
Donations	1,414	2,027
Fundraising, sponsorship & licensing contributions	2,007	2,421
All other income (including investments)	213	156
	<b>4,957</b>	<b>6,217</b>

Expenses*	2011	2010
	\$000	\$000
Depreciation	36	5
Cost of service provision (excl. salaries & wages)	1,888	1,576
Administration cost (excl. salaries & wages)	657	528
Salaries & wages	2,451	2,129
Fundraising costs	358	343
Impaired assets	-	231
	<b>5,390</b>	<b>4,812</b>
Surplus/(Deficit)	<b>(433)</b>	<b>1,405</b>

\* In the annual review for prior years, administration costs have been allocated to programs/services and fundraising. In accordance with the proposed Australian Charities and Not-for-Profit Commission (ACNC) annual information statement, administration costs are now shown as a separate total.





## Balance Sheet as at 31 December

	2011	2010
	\$000	\$000
Cash	2,554	3,441
Inventory	193	180
All other current assets	320	118
<b>Total current assets</b>	<b>3,067</b>	<b>3,739</b>
Long term investments	715	818
Computers & office equipment	132	163
<b>Total non-current assets</b>	<b>847</b>	<b>981</b>
<b>Total assets</b>	<b>3,914</b>	<b>4,720</b>
All other current liabilities	148	438
All other non-current liabilities	40	20
<b>Total liabilities</b>	<b>188</b>	<b>458</b>
<b>Equity</b>		
Retained surplus/accumulated losses	3,828	4,262
All other equity reserves or funds	(102)	
<b>Total liabilities and equity</b>	<b>3,914</b>	<b>4,720</b>

BCNA maintains an investment portfolio made up of cash and managed funds. This portfolio generates income which assists BCNA to undertake its activities.

The Board, through the Finance, Audit and Risk (FARI) Committee, oversees the management of the investment portfolio.

Our investments in managed funds are long-term investments and are shown at market value. The value of our managed funds investments decreased by \$102k during the year ended 31 December 2011 to \$715k. The Board, with the guidance of our auditors, Ernst & Young, decided to show this decrease as a reserve in the Balance Sheet. The Board believes there is a reasonable prospect the market value of these funds will recover in the medium term.

When making investment decisions, the FARI Committee and the Board follow the requirements of the BCNA Investment Policy. This policy, which is reviewed regularly, details our investment objectives and includes a socially responsible investment strategy. Only funds that take into account environmental, social and human rights, labour standards and other ethical issues will be considered.

BCNA is an Australian public company, limited by guarantee.

ABN is 16 087 937 531.

The Australian Taxation Office has endorsed BCNA as a deductible gift recipient. It is also endorsed as an income tax exempt charity and is entitled to GST concessions and an FBT exemption.

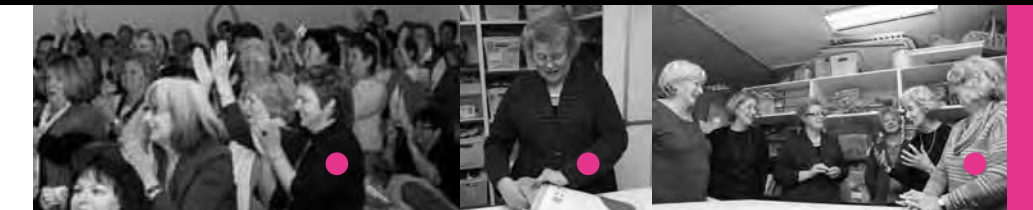
BCNA is a registered fundraiser in each state and territory of Australia.

## OUR ORGANISATION

BCNA is made up of a committed team of staff and volunteers who are passionate about making a positive difference to people affected by breast cancer.

At the end of 2011, we had 32 permanent staff, 10 of whom worked part-time. We also received invaluable support from 41 dedicated volunteers.

We could not achieve what we do without the hard work of our volunteers who help us on a daily basis.



## OUR VOLUNTEERS

Every day of the week, we welcome our generous volunteers into the BCNA office. Some are breast cancer survivors. Many have supported someone with breast cancer. All of them have been personally affected by breast cancer.

The majority of our volunteers have been helping BCNA for several years; two have been volunteering for more than a decade.

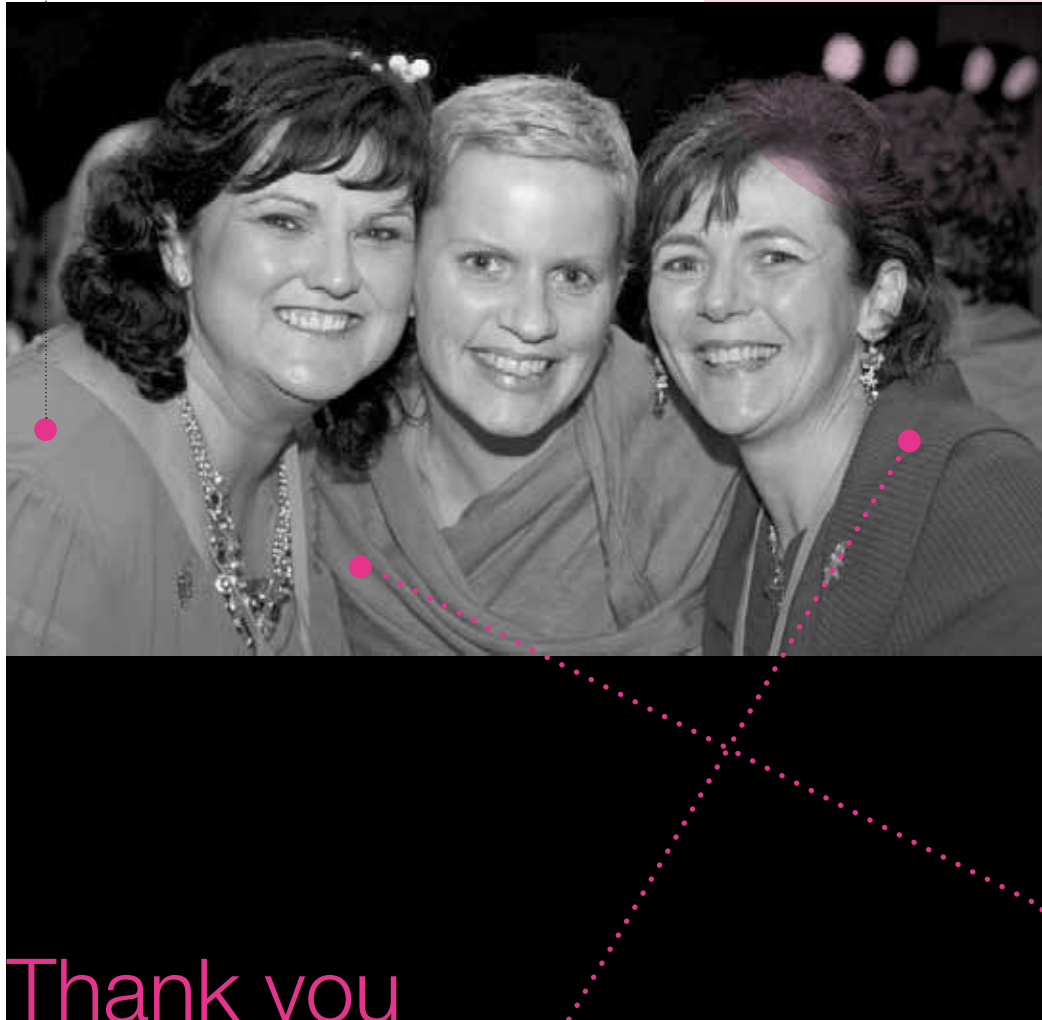
They sort and pack our resources. They contact women whose stories have been chosen for *The Beacon*. They process donations. When we receive returned mail, they ensure our database is up to date. They 'model' our new merchandise items so we can promote them.

At the end of fun runs or during the Pink Bun campaign, it's usually BCNA volunteers who make hundreds of phone calls to personally thank participants and Bakers Delight franchisees across Australia. They help us go that extra step to connect directly with our membership, supporters and sponsors. Our volunteers approach every task with a smile.

Over the years, they have impressed us with their tireless dedication, enthusiasm and warmth. They have made lifelong friends with each other and our staff.

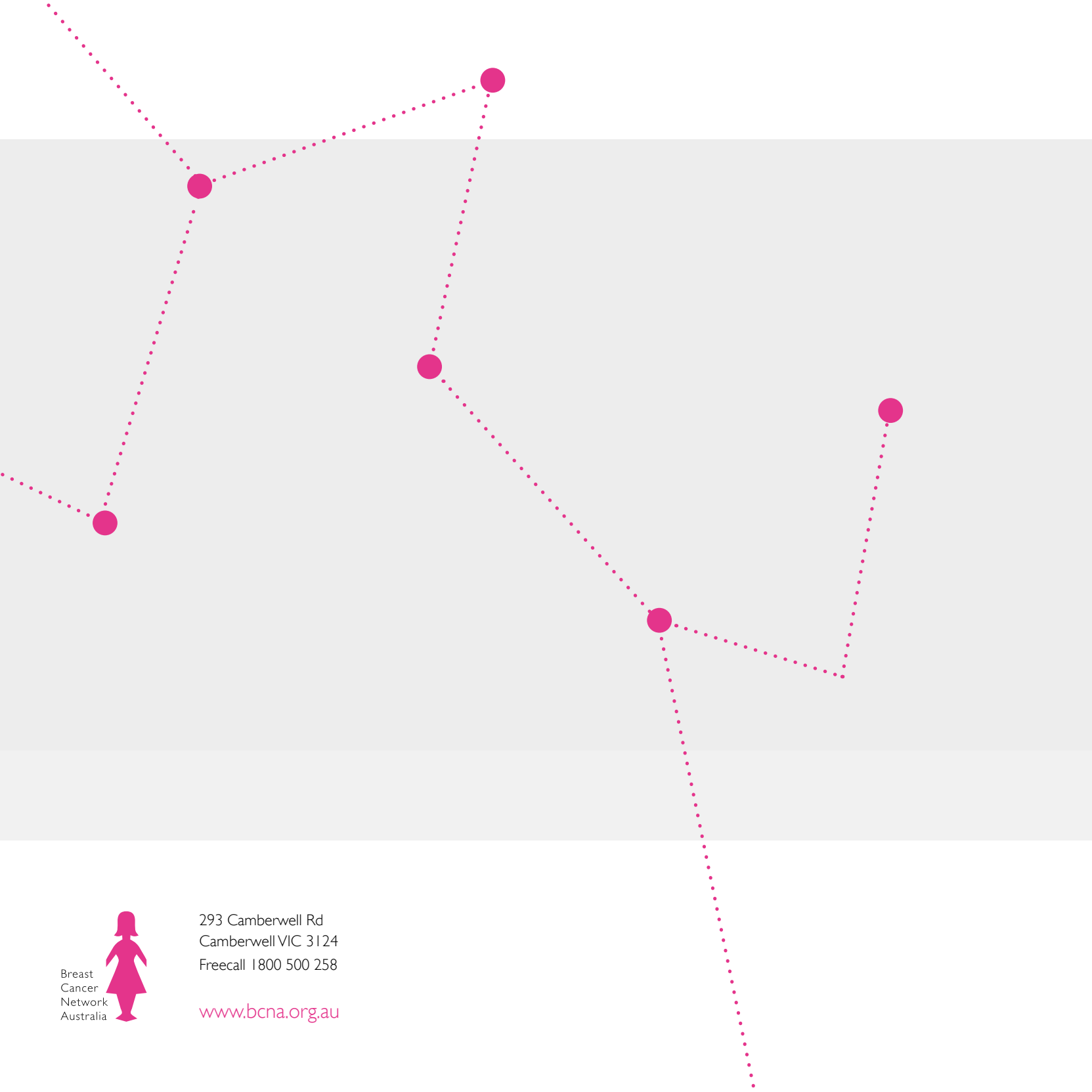
Ultimately, they have made a real difference to our organisation and to women affected by breast cancer across Australia.

*Our Community Liaisons and Member Groups also generously volunteer their time for BCNA across Australia*



Thank you

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Australia

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