



ANNUAL REVIEW 2012



I would like to thank BCNA for all the support as it makes a lot of difference to me to know that there are people who care. – Judith

MISSION

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, 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.



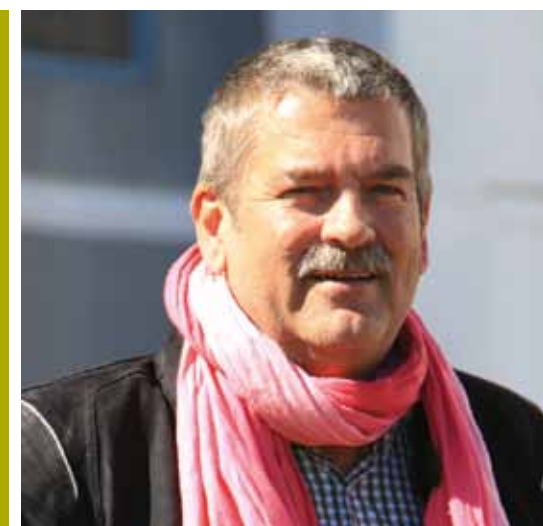
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VISION

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



FROM THE CEO

The increasing number of women diagnosed with breast cancer has meant another busy year of activity for Breast Cancer Network Australia (BCNA) in supporting Australians living with breast cancer.

Every day during 2012, 38 women were told they have breast cancer. What they want to know is why? What can I do? What are my treatment options? What can I do to improve my chance of survival and my quality of life? What about my family? What does it mean for my sisters and daughters? What about my job? How long do I need off work? What are the costs going to be? How will I get through this?

BCNA aims to help answer these and many more questions and offer support by linking women together for mutual support and understanding. Information is vital in understanding your breast cancer and knowing what to ask and how to communicate with your treatment team. BCNA distributed nearly 12,000 *My Journey Kits* and more than 12,000 *My Care Kits* in 2012, which go some way towards providing that vital information and support. In 2012, our website had 1.2 million page views, with an average of 24,000 visitors per month. This demonstrates the need for and importance of quality information.

Communicating with someone else in a shared experience can be of enormous benefit. Our Online Network connected 7,500 members with more than 100 special interest groups. The power of this connection is reflected in the online conversations and the special bonds formed. Great geographical distances are breached by this online connection. There is a growing adoption of online communication in the Australian community and BCNA wants to ensure we can offer the range of connections that our members want and need.

What doesn't change is the value of face-to-face contact. In 2012, 2,500 women attended our 13 community forums across rural, regional and metropolitan Australia to hear up-to-date information from leading clinicians and health professionals.

None of this could have been achieved without our wonderful sponsors, volunteers, supporters, fundraisers, active members of BCNA, our Board and staff. Thank you to all who contributed to the ongoing achievements of BCNA in supporting Australians affected by breast cancer.

Maxine Morand
CEO



L to R: Maxine Morand,
Professor John Boyages,
Elisabeth Black and
Marg O'Donnell

FROM THE CHAIR

Since 1998, Breast Cancer Network Australia (BCNA) has worked tirelessly to improve the experience of those affected by breast cancer. This is an ambitious goal that encompasses the highest quality of information, treatment, care and support.

Each year the number of Australians diagnosed with breast cancer increases. As our population ages the number of new diagnoses will continue to rise. Today, BCNA estimates there are more than 200,000 people living with breast cancer in Australia.

To remain relevant and effective we need to know what those affected want and need. In 2012, BCNA brought together 600 women and their supporters from around Australia to participate in our national conference. We named the conference Strength to Strength because we wanted to acknowledge how breast cancer treatment, survival and outcomes have improved over time. We wanted to recognise how BCNA as an organisation has evolved into an established and influential network. And, importantly, we wanted to pay tribute to the resilience of our members, who constantly inspire us with their strength and determination.

Over the two days I witnessed people talk, learn, connect and network. They represented the diversity of our membership, from their ages and backgrounds to geographic locations. They gave us insight into our members' questions, needs, wants, hopes and fears. They shared an unspoken understanding of what it feels like to go on this journey. They left the conference better informed, supported and empowered.

Breast cancer affects whole communities, not just individuals. As a national network, we draw strength from others. We do not work alone. Our growing membership supports us. Our generous supporters are hard-working and dedicated to our cause. Our sponsors are carefully selected and nurtured over time to ensure a true fit and engagement at all levels.

On behalf of the Board, staff and membership, I thank all of BCNA's supporters over the years and look forward to continuing to work together for the benefit of all people affected by breast cancer.

Marg O'Donnell
Chair

OUR HIGHLIGHTS FOR 2012

66% increase in Online Network membership



More than 2,500 attendees at 13 BCNA community forums across Australia



More than 600 women attended Strength to Strength BCNA's National Conference in Sydney

My Journey Kits reached 81% of all women newly diagnosed with breast cancer

Diversity program initiated to reach women from culturally and linguistically diverse backgrounds

167 Community Liaisons were involved in over 500 activities that raised awareness of BCNA and breast cancer in their communities

315 support groups

Over \$1 million raised by our Major Partner Bakers Delight during the Pink Bun campaign



More than 75,000 members Australia-wide



Strengthened long-term relationships with our key sponsors and supporters

Launched Hope & Hurdles updated resource pack for women with secondary breast cancer



Strategic Advisory Group of leading health professionals established to help inform and support BCNA's work

OUR BOARD

Marg O'Donnell (Chair) a

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 and again in 2011.

Andrew Barling b

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.

Professor Fran Boyle AM c

Fran is a Professor of Medical Oncology at the University of Sydney and is involved in the care of women with breast cancer at the Mater Hospital in North Sydney, and in teaching and research. She is also the Medical Director of the Pam McLean Communications Centre at the University of Sydney, training health professionals in better communication. Fran chairs the board of the Australia New Zealand Breast Cancer Trials Group and represents Australia in the international breast cancer research community. In 2008, Fran was appointed as a Member of the Order of Australia for her contributions to breast cancer research, policy, education, advocacy and care.

Raelene Boyle AM MBE d

As a track and field athlete, Raelene was selected to represent Australia at four Olympic Games, attending three of them. She 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 and 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 AM (Deputy Chair) e

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 and on the board of the National Film and Sound Archive. Terry received the Order of Australia in 2012, 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.

Michael Happell f

Michael has been a Partner with PricewaterhouseCoopers for over 20 years and is currently the Global Relationship Partner for BHP Billiton and Chairman of the Australian firm's Board of Partners. 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. Michael is a director and treasurer of the Melbourne Cricket Club and a school council member and Chair of Risk at Scotch College, Melbourne. Michael has three daughters and is married to Tatty, who is a breast cancer survivor.

Karen Hayes g

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 h

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 Forum, 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.

Professor Christobel Saunders i

Christobel trained as a doctor in the United Kingdom moving to WA in 2000. She has been Professor of Surgical Oncology (2002), academic surgeon, cancer researcher and teacher of surgery at the School of Surgery, University of Western Australia. Christobel is President of the Cancer Council WA, Advisory Council and Board member of Cancer Australia, inaugural Director of the State-wide Cancer and Palliative Care Network, and authored the WA Health Cancer Services Framework. She has substantially contributed to many clinical aspects of breast cancer research including clinical trials of new treatments, psychosocial, translational and health services research.

Gabrielle Trainor j

Gabrielle has been a non-executive director and chair of a range of public, private and not-for-profit entities for 20 years. She was a founding partner and a managing director of John Connolly & Partners, a specialist issues management firm which advises top 20 ASX listed companies. She is Chair of the National Film and Sound Archive and a director of organisations including Leighton Contractors (advisory board), the Barangaroo Delivery Authority, the Greater Western Sydney Giants Australian Football Club and the Whitlam Institute in the University of Western Sydney. She is an Honorary Associate of the Graduate School of Government at the University of Sydney.

We work together and draw on each other's strength, passion and experience to give our members hope, support, information and knowledge.

– Karen Hayes, BCNA Board member



OUR MEMBERS

Breast Cancer Network Australia's membership comprises people from around Australia who have been affected by breast cancer. They include women and men who are newly diagnosed, undergoing or finished treatment, and people living with secondary breast cancer. More than 90 per cent of our members have had a breast cancer diagnosis. The remaining members have been affected by breast cancer through the personal experience of a family member or friend.

A diagnosis of breast cancer marks the beginning of a journey for each person and the people around them. It's a journey that BCNA shares with our members, and we work to provide the information and support that our members need at different stages.

In 2012, our membership grew to more than 75,000.

BCNA members State by state

ACT	1,465
NSW	23,713
NT	436
QLD	15,102
SA	5,935
TAS	2,270
VIC	20,094
WA	6,624
Total	75,639



Thanks for the opportunity to participate in the Monash Medical Student activity. Being face to face with medical students is enlightening for all parties. They get to understand the patient perspective and we get the opportunity to also understand the myriad of demands on their time, and together we can make the process better.

– Kym



Connecting with our members

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

Community Liaisons

Our Community Liaison program, established in 2007, is made up of volunteers who have had a breast cancer diagnosis and who want to give back to their communities and help others.

Community Liaisons speak about their own personal experience with breast cancer and represent BCNA in their local communities.

BCNA provides a training program and ongoing support to ensure that these women:

- are confident talking about their personal breast cancer experiences
- have a greater understanding of BCNA and the roles of the four key national breast cancer organisations
- have the skills and strategies to raise awareness about breast cancer and BCNA in their communities.

In 2012, we trained 36 new Community Liaisons. There are now 228 BCNA Community Liaisons around Australia, speaking at community events, making sure local health professionals know about BCNA's resources and support, talking to local media, and organising information displays at public events.

Community Liaisons keep us connected with the local breast cancer related issues and keep us informed about what women want and need throughout their breast cancer journey.

We received funding through the Australian Government's *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program* to help us train the 19 women from rural and regional areas.

Highlights for our Community Liaison program in 2012 include:

- 36 women trained as BCNA Community Liaisons – 19 live in rural and remote locations and two are Aboriginal women
- 167 Community Liaisons were involved in more than 500 activities that raised awareness of BCNA and breast cancer in their communities
- Community Liaisons conducted education experiences for undergraduate medical students at Monash and Melbourne universities.

47% of our Community Liaisons are from rural and regional communities.

Member Groups

BCNA's reach into communities is one of our greatest strengths. Our Member Groups are primarily community-based support groups that offer practical help and assistance to women living with breast cancer. They support women and families through conversations, education and shared experiences.

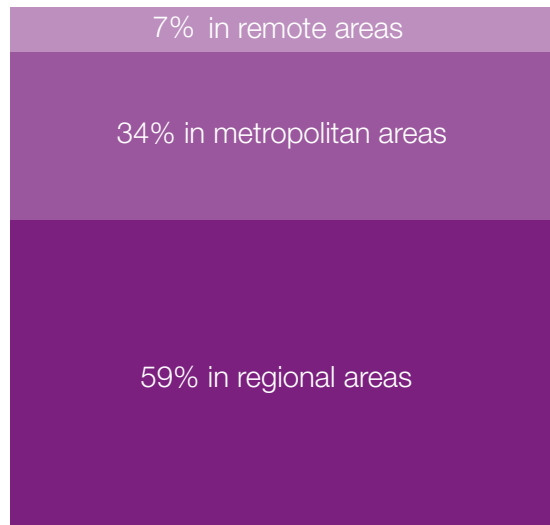
This year we registered 34 new Member Groups, bringing the total number to 315 (a 9 per cent increase from last year). As more Member Groups register with BCNA, our network of women supporting others across the country grows and strengthens. Importantly, Member Groups promote our resources and services to their communities and get involved in our *Mini-Field of Women* and *Pink Lady* events.

This year 64 Member Groups participated in *Mini-Field of Women* events, raising their own profile and that of BCNA. In addition, 43 Member Groups were involved in forums across Australia. Women from the groups helped us plan the forums, promote and set up the events and welcome the participants. This built stronger links between groups and BCNA and between groups and their communities.

BCNA also provides Member Groups with micro-sites within the BCNA website to help women find support groups in their area based on a simple postcode search. The micro-sites give groups their own website, which many of them could not afford to have designed themselves. Groups can promote who they are, what they do, upcoming events, share their stories and include photos of events. In 2012, 81 groups managed their own micro-sites.

I have been with BCNA since it started. The many conferences and training sessions have been so very valuable and placed me in good stead to continue leading my group. BCNA has always been there, through thick and thin, and their knowledge is amazing.

– Noel, Daffodils Breast Cancer Support Group, Vic



I love The Beacon! I share it all the time, photocopying bits for friends to help them cope personally or to assist others cope with breast cancer. Thank you for your wonderful publication. – Fiona

Thank you very much for the bra that I received. It fitted me well and it helped to support my healthy breast and shape my reconstructed breast after my mastectomy. I would like to thank BCNA for all the support as it makes a lot of difference to me to know that there are people who care. – Judith



OUR SERVICES

Delivered directly to women

BCNA works to ensure women with breast cancer feel informed and supported. We provide a range of free information, as well as opportunities for women to connect online or in person at forums held throughout metropolitan, regional and rural Australia. Some of our services are provided at significant milestones in a woman's breast cancer journey; others are available for women many years out after their diagnosis.

My Care Kit

Through BCNA's partnership with Berlei, we provide a free *My Care Kit* to women who have recently undergone breast cancer surgery. The kit contains a specially designed Berlei bra and soft forms, and is ordered through breast care nurses and other health professionals with whom BCNA maintains strong ongoing relationships.

In addition to a Berlei bra, each *My Care Kit* contains a Pilates exercise DVD program that helps women regain strength, and ease discomfort, after recent breast cancer surgery. The 'Strengthen your recovery' DVD was produced with the assistance of Estee Lauder.

A total of 12,104 were distributed during 2012.

This is an average of 232 kits per week and represents a 9 per cent increase on 2011.

83% of women diagnosed with breast cancer in 2012 received a *My Care Kit*.

The Beacon and The Inside Story

The Beacon and *The Inside Story*, our free quarterly magazines for BCNA members, are led by the voices and experiences of women and feature their personal stories. They contain up-to-date information about breast cancer, events, programs and issues of importance to our members.

More than 300,000 copies of *The Beacon* and 28,000 copies of *The Inside Story* were distributed in 2012.



My Journey Kit

One of BCNA's key resources is the *My Journey Kit*, a free resource for women newly diagnosed with early breast cancer. The kit provides information and practical advice and was developed with input from women who have experienced breast cancer, and from a range of health professionals.

In 2012, we distributed 11,795 *My Journey Kits*; an average of 227 per week. This is an increase of 2 per cent on our 2011 distribution.

Based on projected incidence of breast cancer, we estimate that *My Journey Kit* reached 81 per cent of women diagnosed in 2012. By the end of December 2012, more than 77,000 kits had been distributed to women since the kit was launched in 2004.

Most kits (83 per cent) were received by women within four weeks of diagnosis; 37 per cent of those were received within one week. Seventy-one per cent of kits were ordered by breast care nurses on behalf of women in their care. We continue to maintain strong relationships with breast care nurses, who play an important role in connecting women with BCNA.

Hope & Hurdles

Hope & Hurdles was first developed by BCNA in 2007 to address the unique information and support needs of women living with secondary breast cancer, recognising that they faced very different issues and challenges.

The updated second edition of *Hope & Hurdles* was produced after extensive consultation with women living with secondary breast cancer and the clinicians who treat and care for them. It now consists of a core pack of information (including booklets, CDs, magazines and brochures) and additional optional items that allow the resource to be tailored to the individual's needs. Separate booklets about secondary breast cancer in the bone, liver, lungs and brain, and about facing end-of-life issues can be ordered by women at any time.

The second edition of *Hope & Hurdles* was launched in September 2012 at a special forum in Melbourne, attended by more than 150 women with secondary breast cancer, their partners and supporters.

In 2012, we distributed 956 *Hope & Hurdles* packs; an average of 18 per week. This represents an increase in distribution of 23 per cent from 2011.

By the end of 2012, 5,434 packs had been distributed since *Hope & Hurdles* was first launched in 2007.

I ordered My Journey Kit on Sunday night and received it on Wednesday. I just had to say how fantastic this kit is. I cried with happiness when I opened it. So much information and so easy to understand. The books are so beautifully presented and I know I will be constantly referring to them. The CD is so thoughtful as are the pamphlets for friends and work colleagues. Thank you from the bottom of my heart. – Joan

Thank you very much for the Hope & Hurdles pack. It has been really helpful, especially the brochure on secondary breast cancer in the brain. It's really good and really helped me with a lot of my questions. I wish someone had given it to me at the hospital. The whole kit is fantastic. I've learned heaps by reading it. I now feel there is a lot of hope for me. – Vicki

Fact sheets and booklets

BCNA also offers a range of information sheets and booklets on various topics members are interested in, such as pathology, lymphoedema, family history, sexual wellbeing, travel insurance and depression. In 2012 we produced the following new booklets:

- *Breast Cancer and Exercise* – containing information on the benefits of exercise, the amount of exercise recommended for women diagnosed with breast cancer, practical strategies to stay motivated, and an exercise diary. The booklet also contains information on diet and weight loss.
- *Hormone Therapy and Breast Cancer* – explaining how hormone therapies work, why they are so effective at preventing breast cancer recurrence, and providing tips for women on how to manage some of the side effects.
- *Menopause and Breast Cancer* – explaining why some treatments, including chemotherapy and hormone therapies, may cause menopause or mimic menopausal symptoms. It also outlines numerous tips for women on how to manage these symptoms.

All of these booklets were developed with the assistance of women with breast cancer and health professionals.

Connecting online

Our online services strengthen our relationship with our membership, enhance our ability to link people together, promote BCNA's services and programs, and raise awareness about breast cancer, treatment and support available. Our website features stories by women who have experienced breast cancer, with tips on how they have coped. It also links to other trusted websites and resources.

During 2012 there was significant traffic and growth with an average of 24,030 visitors per month, an increase of 45 per cent from 2011 (16,607) and more than 1.2 million page views.

We continued to develop our online services to meet the needs of our members and the general public, and to be even more engaging, easier to use and faster than ever before.

Online Network

Our Online Network, launched in 2010, is one of the first examples in Australia of social networking for a specific health issue. It connects people around Australia and it is especially useful for women in rural and remote areas and for those who feel more comfortable sharing their thoughts, feelings and fears in a secure online environment.

The Online Network continued to thrive with more than 7,500 members (39 per cent from outside a major city of Australia). More than 100 online interest groups evolved through the network.

I have found this site invaluable and I don't know what I would have done without the support I receive here. It's nice to talk to people who understand exactly what I am going through and to vent to people who aren't family. – Amy

Local Services Directory

In late 2011, we launched the online Local Services Directory to help people find and recommend services and support in their local community. By the end of 2012 the directory featured more than 500 listings, 290 of which were added in 2012. They include support groups, wig libraries, specialist bra fitters, counsellors and other recommended services.



45%

increase in visitor traffic to BCNA's online resources in 2012.

Community Forums

People who attend BCNA's free Community Forums tell us that there is nothing more empowering and comforting than sitting in a room full of women and supporters who have travelled or are travelling a similar road. We hear time and time again that our forums are a great opportunity to share stories, have a laugh and meet other local women diagnosed with breast cancer. They also value the chance to learn about the latest in breast cancer treatment and research, and hear about services available in their community. More than 2,500 women, partners, family and friends attended our 13 free BCNA forums in 2012. We travelled to regional and rural Alice Springs, Orange, Cairns, Warrnambool, Toowoomba, Bundaberg, Lismore, Gold Coast and Bunbury, and metropolitan Perth, Melbourne and Adelaide.

In 2012, we introduced a forum especially for women living with breast cancer and their supporters, to coincide with the launch of our new *Hope & Hurdles* pack. This event proved extremely popular and similar forums will be offered in the future.

Our focus on reaching women living in rural and remote areas was funded by the Australian Government as part of the *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*.

We thank the dedicated health professionals – including leading medical oncologists, psychologists, psychiatrists and breast care nurses – for giving up their valuable time to travel and present at our forums: Dr Richard de Boer, Professor Fran Boyle, Donna Cook, Dr Michelle Cronk, Dr Joanna Dewar, Kathryn Devantier, Stephanie Dowrick, Dr Jane Fletcher, Rachel Gorrell, Sandra Gregg, Helena Green, Rebecca Hay, Dr Theresa Hayes, Judith Iasiello, Jo Kelaart, Denise Kiff, Bronwyn King, Susan Kuter, Dr Carrie Lethborg, Margaret Mears, Dr Nicole McCarthy, Heather Rogers, Professor Christobel Saunders, Dr Catherine Shannon, Cathie Smith, Marion Strong, Dr Ru-Wen Teh, Associate Professor Jane Turner, Associate Professor Nicholas Wilcken.

Reaching women from diverse backgrounds

In 2012, we started our dedicated strategy to enable women with breast cancer from culturally and linguistically diverse backgrounds to access information and support. We reviewed research, analysed data, surveyed breast cancer health professionals and gathered existing information on breast cancer in various languages.

We consulted with representatives from culturally specific communities and multicultural peak bodies, and drew on the experiences of other health organisations that have developed similar initiatives. Many agencies in the cancer and multicultural sectors encouraged our efforts, and we will continue to work with them to influence and deliver our culturally appropriate programs for women in the future.

OUR VOICE

With a strong membership base, BCNA gains significant insight into the needs of women affected by breast cancer.

We listen to what they want and work to ensure that their needs are represented and voices heard wherever important decisions are made.

Our best results are achieved by working with policy makers, health professionals, researchers, breast cancer and other cancer organisations, and government.



Strength to Strength national conference

In October 2012, we hosted Australia's largest breast cancer consumer conference over two days in Sydney. Strength to Strength ran concurrently with the Sydney International Breast Cancer Congress (SIBCC) for breast cancer clinicians and was held in conjunction with the Westmead Breast Cancer Institute. The conference brought together women affected by breast cancer, health professionals and researchers to listen, learn and debate the key issues in breast cancer.

The conference explored issues and topics important to women affected by breast cancer, and was an opportunity for women to:

- listen to international, world-leading authorities present on the latest breast cancer research
- learn more about breast cancer treatment and care and ask questions of the experts
- connect and network with more than 600 women with breast cancer across the country
- feel more empowered to make informed decisions about treatment, care and lifestyle choices
- find support in a warm and positive setting
- come together as a united voice.

Government funding allowed us to provide financial support for 150 women and health professionals from rural and remote locations to attend. Our long-term sponsor Sussan generously assisted 20 leading women from metropolitan areas to attend.

Importantly, BCNA heard about the issues and concerns of women from around the country. This will help inform our policy work in the future.



84% of women who attended BCNA forums in 2012 did so to learn more about breast cancer.

93% told us they left feeling much more or more informed.

This forum was unbelievably helpful and I thoroughly enjoyed every moment of it. The information and support was great, and made me realise I am not alone.

– BCNA forum participant, Lismore





Photo: courtesy Great Lakes Advocate

Advocacy

In 2012, BCNA worked with various organisations to get the best outcomes for women across a range of issues. Our policy and advocacy work ultimately aims to address the significant and often complex range of issues and challenges that arise following a diagnosis of breast cancer.

We understand that the issues women face while undergoing active treatment such as surgery and chemotherapy differ greatly from the issues experienced by women many years past their original diagnosis. Longer term issues include side effects of treatments, emotional and sexual wellbeing, and the financial impact of a cancer diagnosis.

In 2012, we lodged submissions with the Medical Services Advisory Committee in support of applications for new or increased Medicare rebates for:

- MRI scans for young women who have had a diagnosis of breast cancer
- Dual-energy X-ray Absorptiometry (DXA) bone mineral density scans for women being treated with an aromatase inhibitor
- single-dose stereotactic radiosurgery for the treatment of brain metastases.

We also lodged a submission with the Pharmaceutical Benefits Advisory Committee in support of an application to list neoadjuvant Herceptin on the Pharmaceutical Benefits Schedule (PBS) for women who require treatment with Herceptin prior to their breast cancer surgery. We were very pleased this application was approved and neoadjuvant Herceptin was listed on the PBS from 1 December 2012.

BCNA also lodged submissions on:

- Victorian Cancer (Reporting) Regulations
- NHMRC Statement on Thermal Imaging
- Cancer Research Leadership Forum: Towards a national cancer research plan white paper.

We also advocated for:

- a national BreastScreen policy which would enable women diagnosed with breast cancer to return to BreastScreen for free annual follow-up mammograms from five years after their diagnosis
- increased travel subsidies for women living in rural and regional locations
- a national model of supportive care for women living with secondary breast cancer.

During the year, BCNA staff attended eight major cancer conferences. A paper on the second edition of *Hope & Hurdles* was given at one conference, and posters on a range of issues, including secondary breast cancer, sexual wellbeing and the importance of consumer representation, were presented at four conferences.

In 2012, BCNA established a Strategic Advisory Group of 14 key health professionals from a wide range of disciplines. This group will help inform and support our work into the future, with many of them also representing key organisations relevant to breast cancer.

Membership is honorary and we greatly appreciate the clinicians giving their time and expertise to help us work together to continue to improve treatment and care for women with breast cancer:

- Ms Elisabeth Black, Specialist Breast Care Nurse, Cancer Nurses Society of Australia
- Professor Fran Boyle AM, Medical Oncologist, Breast Cancer Network Australia Board
- Professor Phyllis Butow, Psychologist, Psycho-oncology Cooperative Research Group
- Dr Mustafa Khasraw, Medical Oncologist, Medical Oncology Group of Australia
- Professor Bogda Koczwara, Medical Oncologist, Clinical Oncological Society of Australia

- Dr Gillian Lamoury, Radiation Oncologist, Royal Australian and New Zealand College of Radiologists
- Dr Helen Frazer, Radiologist, Royal Australian and New Zealand College of Radiologists
- Dr Vivienne Milch, General Practitioner, Cancer Australia
- Dr Chris Pyke, Breast, Endocrine and General Surgeon, Breast Surgeons Society of Australia and New Zealand
- Associate Professor Wendy Raymond, Pathologist, Australasian Society for Breast Disease
- Associate Professor Andrew Spillane, Surgical Oncologist, Breast Surgeons Society of Australia and New Zealand
- Winthrop Professor Christobel Saunders, Surgical Oncologist, Breast Cancer Network Australia Board
- Dr Julie Thompson, General Practitioner
- Associate Professor Jane Turner, Psychiatrist, Psycho-oncology Cooperative Research Group

We understand that the issues women face while undergoing active treatment such as surgery and chemotherapy differ greatly from the issues experienced by women many years past their original diagnosis.



Seat at the Table

BCNA's internationally recognised *Seat at the Table* program ensures decision makers in the national and state health systems are connected to the experience of consumers – the women affected by breast cancer and their families.

We invite, train and support women who have had breast cancer to become BCNA Consumer Representatives. Our Consumer Representatives participate on committees and research panels across the country, and internationally, and are able to contribute the consumer perspective on a wide range of research and program development. BCNA Consumer Representatives have worked with scientists, researchers, clinicians, health service providers and planners since 2000 to improve the provision of treatment, services and care for those affected by breast cancer. They understand the issues important to women with breast cancer and can strongly advocate on their behalf. We currently have 75 trained Consumer Representatives, with 18 (24 per cent) living in rural and regional areas.

In 2012 Consumer Representatives were involved in projects including:

- learning about clinical trials so that they can promote them in the wider community
- contributing to a research project investigating a newly recognised molecular process in cancer metastasis
- ensuring that statements, recommendations and content of clinical practice guidelines relate to the experiences of women with secondary breast cancer
- contributing to a research program examining the translation of specific genetic information into breast cancer genetics services. This involved contributing to the grant application process, communicating and promoting the research, and ensuring that the unique perspective of women at a high risk of breast cancer, and their families, was considered throughout the research
- developing fact sheets that explain the role and process of pathology testing in language easily understood by consumers, including women with breast cancer
- mentoring new Consumer Representatives into the role.

I have been able to contribute to a wide range of research as a consumer representative. I've helped scientists to better communicate their findings to the broader community, resulting in a higher profile for them and increased public awareness of the importance of their research. I have also enjoyed being able to let women with breast cancer know about the research underway that may benefit others in the future. It's very exciting.

– Julia, BCNA Consumer Representative from remote Queensland



My experiences are used to benefit others, and are therefore not lost. Some of the studies also reaffirm just how much I've grown since diagnosis and how well I've handled the whole experience. Sometimes it's good to stop and realise that. Participating in cancer studies helps me do this more often than I would otherwise. – Karen

Review & Survey Group

Research has helped to dramatically improve breast cancer survival, benefiting many women affected by breast cancer today. There is a great diversity of research conducted in Australia, including studies to improve long-term outcomes and quality of life.

BCNA's *Review & Survey Group* is a group of our members who have volunteered to participate in relevant research projects, and help us stay in touch with current experience.

Researchers often approach BCNA with requests to reach women who have had a diagnosis of breast cancer. We contact members of the *Review & Survey Group* once we have reviewed the research proposal for quality, relevance to women and tangible outcomes for women.

In 2012, the number of women involved in the *Review & Survey Group* increased by 90 per cent, from 1,060 to 2,014 and 38 research opportunities were sent out to members.

90% increase in *Review & Survey Group* membership in 2012.

OUR RELATIONSHIPS

Not only do our relationships focus on fundraising, they also play a role in raising awareness and making connections in local communities right around Australia.



Strong connections and relationships are fundamental to BCNA's success. We rely on these to ensure we can reach out and support our members and to help us achieve better results on their behalf.

We nurture close relationships with many organisations and individuals, including professional health organisations, doctors, nurses and supportive care professionals.

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

Government

During 2012 the Australian Government, through its *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*, supported three major 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. Funding also contributes to the development and distribution of our resources, *My Journey Kit* and *Hope & Hurdles*.



Partners and sponsors

BCNA's partners and sponsors raise much needed funds to ensure we can continue to support women with breast cancer. Not only do these relationships focus on fundraising, they also play a role in raising awareness and making connections in local communities right around Australia. We are proud of our long-standing partnerships and have been delighted to welcome new corporates on board in 2012.

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.

We joined together with Australia Post in 2001. It plays a critical role in ensuring the delivery of our information kits to women diagnosed with early and secondary breast cancer.



Berlei's sponsorship of the *My Care Kit* provides a free Berlei bra for women to wear after breast cancer surgery. This successful program reached more than 12,000 women this year. Berlei retailers continue to support us through October through the sale of their specially designed pink bras.

Our partnership with Sussan began in 2006. The Sussan team supports BCNA in many ways and we are particularly proud of the growth of products and information in 2012. This partnership gives Sussan customers an opportunity to support us.

We would also like to thank our corporate supporters for their generous donations:

- Dunlop Flooring
- Ernst & Young Foundation
- Estee Lauder
- Godfrey Hirst
- Harvey Norman – Flooring
- Jellis Craig
- Manildra Group
- NAB
- Peter McInnes Pty Ltd
- Ritchies Supermarkets
- Showcase Jewellers
- Yates.



Generous pro bono support for BCNA from the following suppliers helps us to work more efficiently and cost-effectively:

- Australian Paper
- Channel 9
- Designgrant
- Freehills
- HWL Ebsworth Lawyers
- Multiwall
- Naughtons Transport
- Precision Forme Cutting
- Star Packaging Solutions
- Vega Press
- Yabby Lake.

We thank the organisations that have chosen BCNA to be part of their Workplace Giving programs. In 2012 staff from the following organisations generously supported BCNA: Australian Exhibition and Conferences, BHP Billiton, Blackmores Australia, City of Boroondara, Collins Foods Group, Department of Education and Training – Central QLD Region, Ernst & Young Foundation, Konica Minolta Business Solutions Australia, Macquarie Group Foundation Limited, MLC, National Australia Bank, UXC Australia, Westpac Group and Windsor Recruitment.

BCNA also acknowledges the support of the Australian Charities Fund, Charities Aid Foundation, and United Way Australia for facilitating Workplace Giving partnerships.

OUR FINANCES

BCNA recorded deficits in 2011 and 2012. Despite recording a small decrease in income of 2% during 2012, we are pleased that we were able to reduce total expenditure by 7.8% without compromising the quality of our programs. This control of our expenditure meant we were able to record a small deficit as forecast in our 2012 budget.

The annual Pink Bun campaign, run in conjunction with Bakers Delight, was our financial highlight for the year. The campaign raised in excess of \$1 million for BCNA, more than 20% of our total income for the year.

Our community fundraising income increased during 2012 due to the wonderful efforts of our community fundraisers through *Pink Footy & Netball Day* and during the breast cancer month of October.

17% Australian Government funding represents approximately 17% of total income.

The year 2012 saw a decline in donations compared to 2011, due to a number of factors:

- The number of donors has decreased. It is concerning that our donations are not increasing in line with our membership. We will be seeking to address this decline in 2013 and future years.
- 2011 included a one-off donation of \$100,000 from a corporate sponsor.
- 2011 also included donations received at our major event (Raelene Boyle's 60th birthday party). No major event was held during 2012.

The Australian Government continued its financial support at previous levels for the following programs:

- *My Journey Kit* and *Hope & Hurdles*. New funding agreements were entered into during 2012 which will provide \$1.139 million over three years from July 2012 to June 2015
- *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*. 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.

BCNA maintains an investment portfolio made up of cash and managed funds. This portfolio generates income which assists us to undertake our activities. The Board, through the Finance, Audit and Risk (FARI) Committee, oversees the management of the investment portfolio.

The movement in equity reserves relate to BCNA's investments in managed funds. These are long-term investments and are shown at market value. The value of our managed funds investments increased by \$172,000 during the year ended 31 December 2012 to \$888,000.

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 are considered.

The Board, together with the FARI Committee oversees BCNA's risk management strategy. Risks are identified by examination of operations and activities by senior management. A risk register is maintained and monitored continuously. This register is presented to the Board together with mitigation controls and any further actions required.

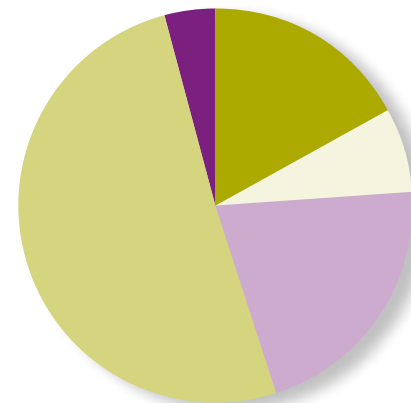
Breast Cancer Network Australia is an Australian public company, limited by guarantee. ABN is 16 087 937 531.

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 and is a registered charity with the Australian Charities and Not-for-profit Commission (ACNC).

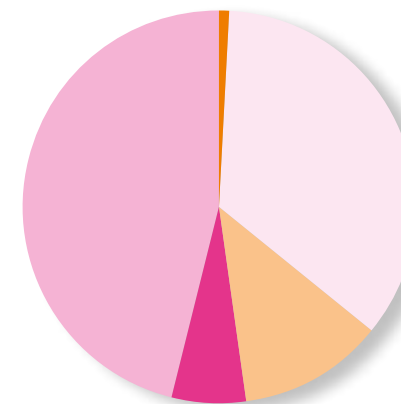
Income and expenditure summary – Year ended 31 December 2012

Income 2012



	2012	2011
	\$000	\$000
Income		
Government grants/contracts	866	823
Income from service provision/trading operations	347	500
Donations	991	1,414
Fundraising, sponsorship & licensing contributions	2,457	2,007
All other income (including investments)	187	213
	4,848	4,957

Expenditure 2012



	2012	2011
Expenditure		
Depreciation	35	36
Cost of service provision (excl. salaries & wages)	1,772	1,888
Administration cost (excl. salaries & wages)	617	657
Fundraising costs (excl. salaries & wages)	253	358
Salaries & wages	2,295	2,451
	4,972	5,390

Surplus/(deficit) (124) (433)

Balance sheet as at 31 December 2012

	2012	2011
	\$000	\$000
Cash	3,121	2,554
Inventory	148	193
All other current assets	122	320
Total current assets	3,391	3,067
Long-term Investments	888	715
Computers & office equipment	108	132
Total non-current assets	996	847
Total assets	4,387	3,914
All other current liabilities	552	148
All other non-current liabilities	61	40
Total liabilities	613	188
Net assets	3,774	3,726

	2012	2011
Equity		
Retained surplus/accumulated losses	3,704	3,828
All other equity reserves or funds	70	(102)
Total equity	3,774	3,726

OUR PROFILE

One of BCNA's key strengths as an organisation is the way we work with communities. Through national and local events we reach out to existing communities around Australia to build our profile and raise essential funds to maintain and expand our programs and services.

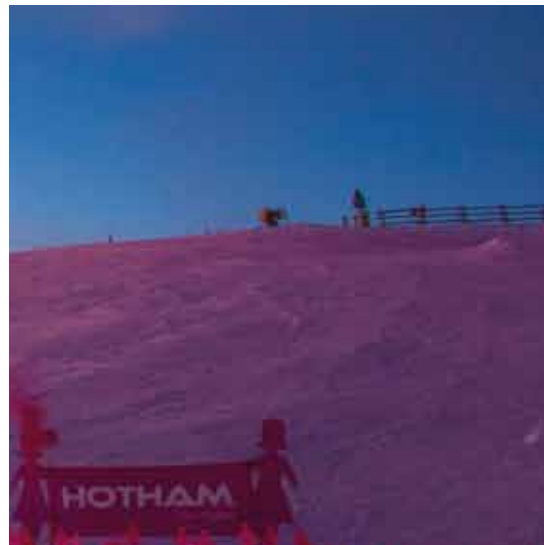
Our *Mini-Fields of Women* were developed in recognition of how important it is for communities to come together to pay tribute to those affected by breast cancer, to remember the people who have lost their lives to the disease, and to provide messages of hope for those at different stages of their journeys. One hundred Pink Lady silhouettes are planted in formation, on which people can leave messages of support. In 2012, 183 *Mini-Fields of Women* were held around Australia, bringing communities together in a powerful and touching way.

Pink Lady events are fundraising events and while their focus is on raising much needed funds, every event must also raise awareness of support within communities and, in particular, the information and assistance BCNA can provide. In 2012, 372 *Pink Lady* events were held. Other fundraising highlights included our *Pink Footy & Netball Day*, and various fun runs such as the annual Sussan Fun Run.

We would like to thank all of the participants, fundraisers, organisers and supporters of these events.

183

Mini-Fields of Women were held around Australia in 2012.



OUR ORGANISATION

BCNA has a dedicated team of 34 staff, who are passionate about delivering programs and support to those affected by breast cancer.

They are supported by an enthusiastic and committed group of 41 office volunteers – women and men who have been personally affected by breast cancer and who help at all levels of the organisation. Combined, our volunteers work 80 hours a week, representing the workload of two full-time staff members. We simply couldn't achieve all that we do without them, and thank them for their good humour, loyalty, empathy and dedication throughout the year.

Combined, our volunteers work 80 hours a week, representing the workload of two full-time staff members.

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