



## TEN YEARS of ACHIEVEMENT

Breast Cancer  
Network Australia  
Annual Review 2008



# Reflecting on ten years



▲ BCNA Chair Patricia Edgar and CEO Lyn Swinburne.

It seems somehow surreal for me to take a step back and see Breast Cancer Network Australia as the thriving, influential organisation it is today, working for the benefit of thousands of women and families affected by breast cancer.

My thoughts return to that first *Field of Women* and our launch in Canberra ten years ago. We had great hopes of positively influencing the way breast cancer was considered – we wanted people to feel they could and should talk openly about the disease, and to acknowledge its enormous personal impact within our community.

We wanted the scientists to stay focused, to keep seeking answers especially to the many questions we had about what might cause the disease and how we might reduce its toll. We wanted the health professionals to see those of us diagnosed as individuals, with individual and changing needs. We wanted timely, quality information presented in such a way that it made real sense and helped us to make the important decisions we needed to make about our treatment and health care.

We wanted them to understand that sometimes it can be the small details of kindness and approach that can make an enormous difference to those at the centre of all this.

We wanted to make sure that breast cancer was fairly and squarely on the agenda of governments and those planning services for us and those close to us.

And, now ten years later, we are able to look back and see how far we've come. We acknowledge that there's always more to achieve, that new issues and needs arise and that we need to keep finding ways to positively influence those who make decisions on our behalf. Importantly, we now see that BCNA has over that time morphed into an organisation which can tangibly and directly help women and their families. The information we offer is based on the real experiences of thousands of women. It can be trusted because we are independent, committed and understand exactly what it is like to hear those words 'You have breast cancer' and then deal with the consequences of those words.

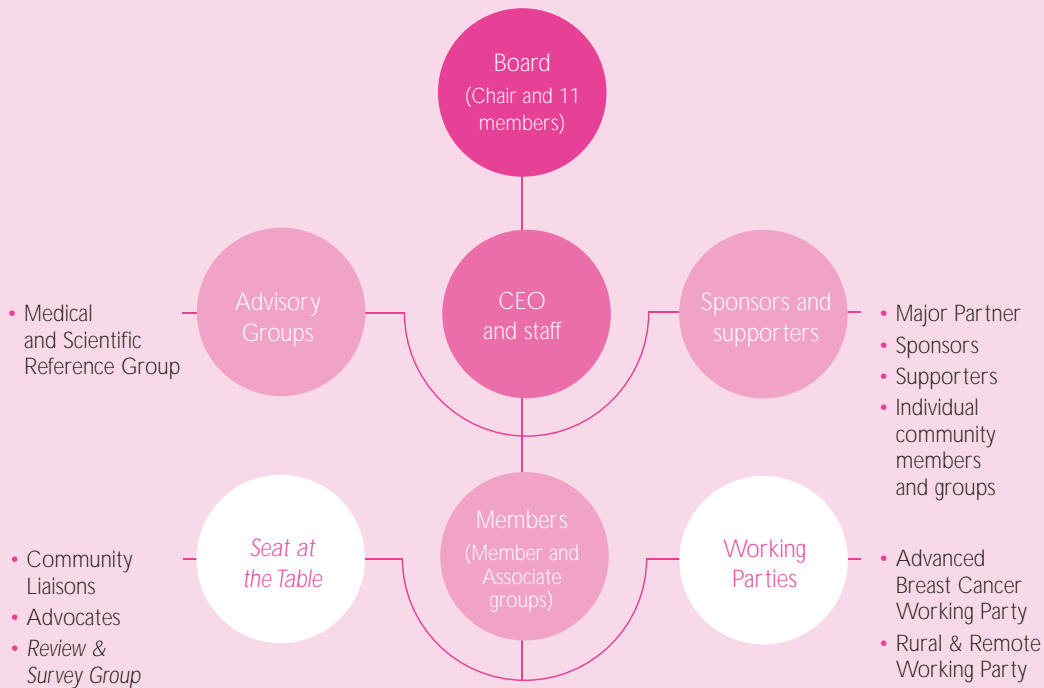
Throughout these past ten years, many women and men have helped form our work and can take credit for maintaining the passion and the focus. At the forefront of these is Patricia Edgar, our Chair from the very beginning, when we were a fledgling organisation full of determination and promise but facing major challenges. Patricia retires in mid-2009, and her thorough leadership, wisdom and contribution as my personal mentor has been considerable. I am pleased to have this opportunity to acknowledge Patricia's significant contribution and to thank her for all her work over the past ten years.

I would also like to pay tribute to the many women with breast cancer who have chosen to direct their energies, sometimes at great personal sacrifice, to build up our organisation, to connect with other women, to speak out about the important issues they face, to represent us on committees, and to help raise funds so we can keep up our important work. Some of these outstanding women have been lost to us through breast cancer. Sadly they are not here to see the vibrant organisation they have helped build, but their legacy lives on. The baton continues to be passed on to women newly emerging as community champions and BCNA advocates, so that while there is always more to be done, there are always dedicated women ready to help others.

I thank all our supporters for the help and assistance you have offered me throughout these past ten years as BCNA's CEO and ask that you keep helping BCNA as we work towards our vision that all Australians personally affected by breast cancer will receive the very best information, treatment, care and support no matter who they are or where they live.

Lyn Swinburne, AM  
Chief Executive Officer

# Organisational structure



## Board



**Patricia Edgar, AM (Chair)**

An author with nine books to her credit, Patricia is best known for her work in children's media. She has served on numerous national committees including Chair of the Australian Broadcasting Tribunal's Children's Program Committee and Deputy Chair of the Australian Film Finance Corporation. She was the Founder of the Australian Children's Television Foundation and Director for 20 years. Patricia chairs the World Summit on Media for Children Foundation. She was diagnosed with breast cancer in 1988.



**Andrew Barling**

Andrew is a General and Thoracic Surgeon working in both rural Victoria and metropolitan Melbourne. In 2000 he established the Otis Foundation, which provides free respite accommodation for women with breast cancer.



**Fran Boyle, AM**

Fran is Associate Professor of Medical Oncology, University of Sydney and Director of the Patricia Ritchie Centre for Cancer Care and Research at the Mater Hospital. She is Chair of the Scientific Advisory Committee of the ANZ Breast Cancer Trials Group. She is also on the Board of the National Breast and Ovarian Cancer Centre. Fran is well known for her contributions to breast cancer research, policy and education and for advocacy on behalf of women with breast cancer.



**Raelene Boyle, AM MBE**

As a track and field athlete, Raelene represented Australia at four Olympic Games. She has won three Olympic Silver Medals, seven Commonwealth Gold Medals and two Commonwealth Silver Medals. One of the National Trust's 100 Living Treasures, Raelene is Patron of Bloomhill Cancer Help on the Sunshine Coast and a member of the Sport Australia Hall of Fame and the Australian Track and Field Hall of Fame. She was diagnosed with breast cancer in 1996.



**Terry Bracks**

Terry has worked in educational and political spheres and she takes an active role in many community, arts and social issues. She is Patron of Heide Gallery, Board member of the Australian Children's Television Foundation and Founding Chair of Western Chances in Melbourne's western suburbs. Terry was awarded an Honorary Doctorate from Victoria University in 2008.



**Ron Dewhurst**

Ron has worked in investment management and investment banking for over 30 years. He is currently Senior Managing Director and Head of International Asset Management with Legg Mason, Inc. He was formerly Head of Americas for JP Morgan Asset Management and CEO of IOOF Holdings. Ron is a Trustee of the National Gallery of Victoria.

## WHO ARE OUR MEMBERS?

*At the end of 2008 we had over 31,000 individual members and 202 Member Groups throughout Australia. Ninety-five per cent of our members have had a diagnosis of breast cancer. The remaining members have had a personal experience with breast cancer such as through a family member or friend.*

# Vision

All Australians diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible, no matter who they are or where they live.

# Mission

Breast Cancer Network Australia (BCNA) informs, empowers, represents and links together Australians personally affected by breast cancer. BCNA:

- **informs** women through a wide range of relevant resources
- **empowers** women to have a voice in their own health care and to play an active role in improving breast cancer treatment, care and services
- **represents** Australians affected by breast cancer in the health care system, scientific community, government, media and wider public
- is driven by women who have themselves experienced breast cancer and **links together** individuals and groups sharing similar issues and experiences.

*In this report we will explore how we have achieved our mission over the last ten years, highlighting ten achievements under each mission statement.*



**Karen Hayes**

Karen Hayes has worked internationally in general management and strategic consulting primarily in financial services and information technology. She was CEO of Planpower and is currently Director Corporate Engagement and Human Capital with UXC Limited. She is also a Melbourne Football Club Board member. Karen was diagnosed with breast cancer in 1996.



**Andrea Hull, AO**

Andrea has been CEO and Director of the Victorian College of the Arts from 1995. She has a background in cultural policy and programs at international, federal and state levels. She is a Board member of the Melbourne Theatre Company, the National Gallery of Victoria and the Abbotsford Convent Foundation. Andrea was diagnosed with breast cancer in 2006.



**Marg O'Donnell**

With a background in social work, Marg 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 first Legal Ombudsman in Victoria. Marg currently works as a consultant and is Chair of Legal Aid Queensland, Chair of the Law School, Visiting Committee, Griffith University, and a member of the Playing Australia Committee. She was diagnosed with breast cancer in 2003.



**Suzie Howie**

Beginning as a publicist with Michael Edgley International, Suzie has worked on more than 700 stage shows, films and cultural events. Since 1985 her public relations company, Howie & Taylor Publicity, has presented productions including Cats, The Phantom of the Opera, Les Miserables, Mamma Mia, Guys and Dolls, and WICKED. Suzie was diagnosed with breast cancer in 2004.



**Jocelyn Newman, AO**

Lawyer, businesswoman, farmer, community worker and politician, Jocelyn was elected to Federal Parliament as a Senator for Tasmania in 1986 and was a member of the Federal Cabinet from 1996 to 2001. She was a member of the National Breast Cancer Centre Board from 2004 to 2007 and was then appointed by the Federal Government to the Advisory Council of Cancer Australia – a position she still holds. Jocelyn was diagnosed with breast cancer in 1994.



**Gabrielle Trainor**

A lawyer, former journalist and public sector executive, Gabrielle is a founding partner of John Connolly & Partners, a specialist issues management firm. She is a director of the Victorian Urban Development Authority (VicUrban), the Sydney Harbour Foreshore Authority and the Sydney Symphony Orchestra. She has chaired and served as a director for a range of government, public, private and not-for-profit organisations.

# To inform

## 1

### OFFERING A BEACON TO WOMEN AND THEIR FAMILIES

*'Thank you for The Beacon. As a breast cancer "survivor" I find the articles to be inspirational and informative, and can often relate to and empathise with other "survivors":' – Vera, NSW*



Since 1998, our free quarterly magazine *The Beacon* has been the voice of BCNA and our members. Each issue features women's stories, new resources, book reviews and issues relevant to women and their families, so they can make informed decisions during their breast cancer journeys. We hear from many women who describe *The Beacon* as their 'lifeline'.

At the end of 2008 we had over 36,000 subscribers to *The Beacon*. In the last few years we have seen an increase in the number of health professionals subscribing to *The Beacon*, which indicates that BCNA also plays an important role in informing health professionals about the key issues affecting the people in their care.



## 2

### A ROAD MAP FOR THE JOURNEY AHEAD

*'The information in the My Journey Kit made me realise that my journey was do-able.'* – Sue, Qld

When a woman is diagnosed with breast cancer, her world is tipped upside-down. Information, services and supports are available for these women, but the challenge is to work out where they are and how to access them quickly. To assist newly diagnosed women, BCNA launched the *My Journey Kit* in 2004. The Kit includes signposts to useful services, handy practical tips, references to great websites and has a comprehensive *Information Guide* and *Personal Record* for women to use as needed, and to help inform their family and friends. It has been compiled with input from hundreds of women who know what it's like to be facing this major challenge at a very vulnerable time.

The Kit is free for women and is delivered to their home within one week of ordering.

BCNA's aim is that women receive their *My Journey Kit* as close as possible to their diagnosis, so they can make informed decisions about their treatment options.

*'I think that the Kit and what is presented in it is excellent. I believe it is well written, reassuring, and very balanced in the information that is presented. I thought the surgery part was particularly good and written in a balanced manner. I would be happy for any of my patients to receive such a Kit.'* – David, Breast Surgeon

# 3

## PROVIDING THE INSIDE STORY FOR WOMEN LIVING WITH SECONDARY BREAST CANCER

*'I look forward to The Inside Story arriving, it is such a special magazine. I feel so supported and it inspires me to not feel alone.'* – Cathie, Qld

In 2006 we introduced *The Inside Story*, a four-page supplement to *The Beacon* for women living with secondary breast cancer, and those close to them. We acknowledge that these women may experience different issues and may face more complex challenges to women with early breast cancer. The supplement features women's powerful stories, new resources and book reviews, and updates on the latest treatments and trials.



# 4

## MAKING IT PERSONAL IN THE MEDIA

*'The media can bring us the latest information but the women's stories are what makes the story memorable and real for me.'* – Barbara, SA

It is always a BCNA priority to present the personal face of breast cancer in the media. Communicating via the media is an opportunity to add strength to BCNA's advocacy work, to highlight the reality of issues faced by women with breast cancer and those close to them and to help us work for better treatments and care for our members.

We have used community-based media to reach women and inform them about our resources, events and services available to them at a local level.

# 5

## INFORMING THE PEOPLE AROUND THE WOMAN

Over the last ten years BCNA has developed a number of information brochures and fact sheets which are available free of charge for women and their family and friends.

Helping a friend or colleague with breast cancer is our most popular brochure and is often requested by employers and HR managers wanting to support staff members who are diagnosed with breast cancer.

*'The Helping a friend or colleague brochure was an easy way for my manager to let my concerned work colleagues know what they could do to support me.'* – Jane, Vic



*'Both my partner and I have read How can I support her, and think it is excellent. Indeed I would like to see it distributed to the entire population, to give people some real insight into just what people with secondary cancer do and do not want'* – Lorna, Qld

Many women have shared with us the challenges they faced explaining secondary breast cancer to family and friends. We produced *She has secondary breast cancer – how can I support her?*, a booklet for partners, relatives and friends, which explains what their loved one is facing, and how they can not only support her, but also take care of themselves.

## 6

### INFORMING WOMEN DIAGNOSED WITH SECONDARY BREAST CANCER

*'I had been hungry for information ever since I was diagnosed with secondary breast cancer. The pack provided important information from other women about things that I did not find out from medical practitioners or hospital services.'* – Lyn, SA

The *Hope & Hurdles* Pack was launched in August 2007. The information, contacts and references in the Pack are specifically designed for women whose cancer returns in other parts of their bodies. Historically, information for these women had been very scant. They had told us how lost and alone it felt to be given this diagnosis without key information about help they might be able to receive for themselves and their families.

Crucially the *Hope & Hurdles* Pack is full of life-affirming messages from many women also living with this form of the disease.

*'It gave me instant hope to know that others are still alive who have a similar diagnosis to me.'* – Debbie, Vic

Like the *My Journey Kit*, the *Hope & Hurdles* Pack has been endorsed by all relevant medical colleges. These are listed on page 25.

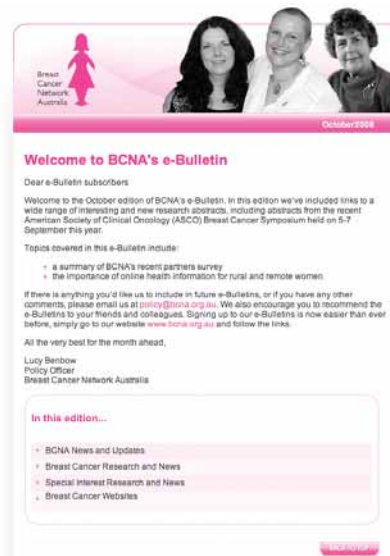
*'This is another excellent and ground breaking publication from your organisation. It was highly informative, well written, easy to understand for consumers and focused around what seemed to reflect women's concerns, rather than just providers' issues.'* – Tony McBride, CEO, Health Issues Centre



## 7

### INFORMING WOMEN VIA E-BULLETINS

*'Thank you for your regular e-Bulletin. They are very informative, and I appreciate receiving them.'* – Sally, Qld



Knowledge gained from around the world as a result of breast cancer research, trials and conference presentations is constantly developing. In 2007 we launched our *e-Bulletins* to provide women and health professionals with summaries of the latest breast cancer research findings, including electronic links to abstracts and research journals.

The *e-Bulletins* are emailed once a month and include a particular focus on four different themes around breast cancer:

- young women
- women in rural and remote locations
- women with a family history
- women with secondary breast cancer.



*'The power of informed consumers has been realised. BCNA has influenced policy, treatment guidelines and actual treatment practices, and taught us that we must listen to our patients and understand their needs.'* – Associate Professor Richard Bell, Medical Oncologist

### What women want: Information needs following a diagnosis of early breast cancer



**Introduction**  
Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer. The My Journey Kit, launched by BCNA in 2008, is a unique information resource, developed by and for women with breast cancer. The Kit contains:

- the My Journey Information Guide
- the My Journey Personal Record
- the National Breast and Bowel Cancer Nurses' (NBCCN) Kit pack for women with early breast cancer
- a range of pamphlets on various aspects of breast cancer

**Method**  
In 2008 BCNA undertook an evaluation of the My Journey Kit. Three hundred women who had received the Kit in 2006 were randomly selected from BCNA's database and mailed a written survey which included a combination of closed, multiple-choice, open questions and open-ended, qualitative questions.

**Results**  
**About the women**  
One hundred completed surveys were returned. The age of the women (MCM) received surveys was slightly younger at first diagnosis than the national age of women diagnosed with breast cancer.



**My Journey Kit**  
The first steps taken following my diagnosis. I wanted to be getting kit and piece of information from everywhere and here was a wonderful kit which answered in many of my questions."

Overall, respondents reported that:

- the My Journey Kit has 'got the right amount of information' (78%)
- the information in the Kit is 'easy to read' or 'very easy to understand' (79%)
- it is 'useful or very useful' for first information in the Kit (85%)

Ninety per cent of respondents stated that it was 'important' or 'very important' that the My Journey Kit was put together using responses from women with breast cancer.

Women used the My Journey Kit the most during their treatment.

Seventy four per cent of women received an additional copy of the NBCCN kit. However 56% of respondents thought it should still be included in the Kit as it provides a different perspective to the My Journey Information Guide.

The majority of respondents (76%) found out about the Kit from a breast care nurse, while 10% of women said their surgeon told them about the Kit.

Women commented that most course doctors and health professionals should be encouraged to promote the Kit to women.

*"It would have been very helpful if my surgeon had been able to give me a My Journey Kit or to suggest that I contact Breast Cancer Network Australia."*

**My Journey Personal Record**  
Sixty seven per cent of women surveyed stated that they had returned information in the Personal Record at some stage of their journey.

*"I found it (the Personal Record) great as a way of answering questions to ask and particularly to log how I felt after treatment."*

**My Journey Information Guide**  
The women of the My Journey Information Guide that women found 'very' or 'quite helpful' are:

- Ways to deal with the emotional aspects of my diagnosis (79%)
- How to dealing with the other breast cancer (76%)
- Information about diet and exercise (77%)
- Information for partners and family (78%)
- Support for living and getting the most out of my medical team (74%)

Despite the information being specifically targeted to women, approximately 20% of early breast cancer friends or colleagues also read the My Journey Information Guide.

Seventy three per cent of women reported that they used the Guide 'very often', 'often' or 'regularly' and 4% of women said they could refer to it 'on occasion', defined as referring to it on a number of occasions.

*"I found the My Journey Information Guide very easy to read and helpful when I was feeling my life was on loan... I did need to refer and after my treatment and here it was hand all I need it."*

**What women compared to the distribution of new cases of breast cancer, respondents agreed the national respondents lived in a city or metropolitan area, highly more respondents living in a rural area, and approximately the same distribution of respondents across Australian states and territories.**

For more information or for a free sample My Journey Kit contact Laine Howard or Michelle Marlow on 1800 500 258 or email [bcna@bcna.org.au](mailto:bcna@bcna.org.au)  
Women can order a free My Journey Kit online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1800 78 55 62.

[www.bcna.org.au](http://www.bcna.org.au)

BCNA's My Journey Kit poster presented at the Leura conference.

# 10

## PROVIDING A QUALITY INFORMATION HUB



# 8

## OFFERING AND GAINING INFORMATION AT CONFERENCES

From the beginning, BCNA has seen significant value in a strong presence at targeted national and international breast cancer conferences. They are an opportunity to develop our knowledge of the latest clinical trends and options available to women. We have been able to share women's experiences of breast cancer with those who deliver treatment and care; and inform breast surgeons, oncologists, nurses and other health professionals about the real issues faced by women.

Staff and our representatives attended a range of conferences in 2008 including the European Breast Cancer Conference in Berlin, the 10th National Breast Care Nurses' Conference in Fremantle, WA, and the 6th Leura Breast Cancer Conference in Sydney. During the Leura conference, which is only held every four years, BCNA presented posters (pictured), an information display and concluded the event with the Sydney Field of Women LIVE DVD.

# 9

## REFERRING WOMEN TO SERVICES AND FURTHER SUPPORT

*'It is difficult to know where to start, so I was so grateful when I rang BCNA and they were able to help me find the services I needed and send me some useful information.'* – Glenda, WA

BCNA has a national freecall telephone phone line – 1800 500 258. Our Enquiries Team take calls and respond to emails from women, family members, health professionals and the general public. Our role is not to provide professional counselling, but rather to direct callers' queries to trusted BCNA information and refer them to external sources such as the National Breast and Ovarian Cancer Centre and support services in their state or territory.

The calls also offer us an effective way to monitor the issues and needs of people, so that we can work best to address them.

We know that many women and family members use the web to gain information about breast cancer. The web is saturated with information, which at times is misleading; often it is incorrect and dangerous. Our website [www.bcna.org.au](http://www.bcna.org.au) offers a trusted site with links to other trusted and quality websites. A feature of BCNA's website is the profiles written by women who have experienced breast cancer themselves, with tips on how they coped, which offer a real sense that a woman should not feel alone. These pieces can provide great solace, especially in the middle of the night!

The future direction of the website is to embrace new technology, to provide more interactive and tailored information, as well as a social networking environment for our membership.

In 2008 we had 494,050 visitors to the website. Traffic to the website is also continually steady over the 24 hours of the day, with significant international access.

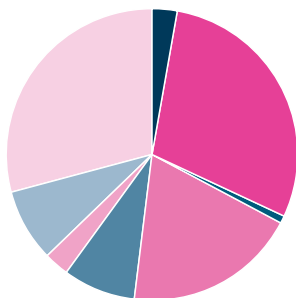
# To empower

## 1

### EMPOWERING WOMEN ACROSS AUSTRALIA

*'It is very empowering to feel a part of a national organisation, feeling you're doing what you can do in your own little way, but also contributing to something much bigger:' – Pat, NT*

Beacon subscribers by state (December 2008)



- ACT – 3%
- New South Wales – 29%
- Northern Territory – 1%
- Queensland – 19%
- South Australia – 8%
- Tasmania – 3%
- Western Australia – 8%
- Victoria – 29%

BCNA was founded in 1998 by a group of women, all breast cancer survivors, who were passionately committed to making a difference for those women who would follow. They wanted to empower women to become active participants in their own health care and recovery no matter where they live.

BCNA's membership has steadily grown over the decade to more than 31,000 at the end of 2008. The location of our membership and *The Beacon* subscribers reflects Australian population trends. This has enabled BCNA to strongly influence the breast cancer agenda across Australia and to speak with authority, drawing from the lived experiences of our membership.



## 2

### EMPOWERING WOMEN TO BE COMMUNITY CHAMPIONS

*'Above all, I have learned that I can make a difference for people, I can make things a little easier and a little better and I can be effective; I would not have believed that possible before I started working with BCNA, it makes a huge difference to who I am.'*

– Jurina, Qld

In 2002 the first Member Liaisons were appointed to promote BCNA at a grassroots level. This initiative has grown into our successful Community Liaison program which by the end of 2008 had 141 committed and active participants, from all states and territories.

Our Community Liaisons are trained to make presentations to local groups and organisations, to represent BCNA in many community-based initiatives and to spread the word about BCNA's information resources and the assistance available to women and families.

▲ Our Community Liaisons Patricia Howes, Donna Vitagliano, Jenny Wantoch-Smith and BCNA supporter Deirdre O'Flynn in action at an event in Sydney.

*'I am so proud to wear my pink vest with our Pink Lady logo. I look back over the past 18 months and dare I say I have to pinch myself at times, never in a thousand years could I have stood in front of a group of people and spoken with confidence, is this really me!'*

– Jackie, Vic

## 3

### SUPPORTING WORTHWHILE INITIATIVES

Over the last decade BCNA has had the opportunity to support a number of worthwhile initiatives led by others which have helped empower women with breast cancer. The *Up Close and Personal2* national conference for young women with breast cancer in Australia, held in Melbourne in October 2007, is an example.

*'Thanks to BCNA we are able to recruit interested and trained consumers to numerous organisations all of whom greatly value their advice. BCNA is an example to other countries.'* – Professor Alan Rodger, Medical Director, UK



The conference was organised by BCNA member group Young Action on Breast Cancer, a small volunteer group of young women. It was attended by 170 young women with breast cancer from across the country. Issues highlighted through the conference agenda and workshops included pregnancy and fertility issues, emotional wellbeing, menopause, dealing with children, sexuality, and life after treatment. BCNA was able to provide support for the conference in a number of ways, including financial assistance, promotions, providing speakers and workshop leaders and writing the official conference report.



▲ Members of the Young Action on Breast Cancer (YABC) committee left to right: Rita Marigliani, AnnMaree Scott, Mary Macheras-Magias, Jo Smith, Kerri Guy and Donna Gordon at the *Up Close and Personal2* Conference held in Melbourne in 2007.

## 4

▲ Rosemary Buchanan, Margaret Venning, Carolyn Vile and Genie Scott are part of the team of volunteers who pack our *My Care Kits* every Friday.

### ASSISTING WITH BODY IMAGE

*'Thank you so much for the bra you sent me. I can't imagine what it would have been like without it. It has made such a difference to my recovery and I can't thank you enough.'* – Peggy, NSW

Every Friday our dedicated team of volunteers pack and post on average 150 *My Care Kit* bras to women across the country, from our office in Melbourne.

Thanks to our long-standing partnership with Berlei, we have provided free bras, especially designed to wear after breast cancer surgery, to over 28,000 women since 2005. This gift offers women support, helping to normalise their lives and give them some confidence at a time when they face life-altering changes.

*'It was a lovely surprise at a time when things felt very strange and difficult, and helped me feel rather cared about. I'm sure this initiative has been appreciated by many others like myself.'* – Trish, Tas

Breast care nurses, who fit women for their correct size and place the bra orders, play an essential role in the success of the *My Care Kit* program.

## 5

### USING NEW MEDIA AS A TOOL OF EMPOWERMENT

*'Mum never really let me believe that she wouldn't be a survivor... Treasure your family for who they are. Do not be scared to show someone your true feelings. Acknowledge your fears but do not let them stop you. Mum has inspired me to reach for great heights, just like she continues to do with each new day.'* – Ben Förster, Digital Story



▲ Ben Förster's family at the Hobart Field of Women in 2003.

In 2005 we undertook the Digital Stories project in conjunction with the Australian Centre for the Moving Image (ACMI). There are 13 individual stories in the series, captured on DVD and told through various eyes – a mother, a son, and women in a variety of situations, including a woman from a multicultural background, a woman living in remote Australia, a young woman and a woman with advanced disease. The stories were developed to reflect the impact that breast cancer has, not just on those diagnosed, but also on those around them.

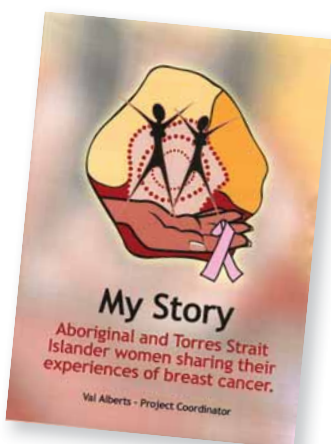
# To empower

## 6

### SUPPORTING COMMUNITY INITIATIVES

In 2002 we established a Community Grants Program to provide funding for individual members and groups to conduct activities in their local communities. Funding of \$100,000 for the grants came from money raised at Raelene Boyle's 50th birthday celebration in 2001.

A diverse range of groups received grants, from women in Tasmania conducting a meditation and healing day, to an education forum in Toowoomba. Indigenous women from Townsville were funded to develop a 'storybook' project, which went on to collect stories from several Indigenous women with breast cancer and to develop a submission for funding a DVD. *My Story* was later produced to inform Indigenous women about breast cancer (pictured).



## 7

### INVOLVING WOMEN DIRECTLY IN FINDING ANSWERS TO BREAST CANCER RIDDLES

*'It was such a privilege to speak to these women. All of them had such amazing and unique stories to share.'* – Jane, Researcher

It is very common for women who have experienced breast cancer to want to make themselves available to researchers in order to help progress our knowledge about breast cancer. In 2007 we established the *Review & Survey* group, to allow women, partners, family and friends to contribute a consumer's voice to breast cancer research studies. Members of the group are notified by email of participation opportunities in research studies including surveys, telephone interviews and focus groups. Members also provide reviews of books, resources, DVDs and consumer information being developed.

At the end of 2008 the *Review & Survey* group had approximately 700 active members.

## 8

▲ Delegates at BCNA's National Member Group Summit in 2006.

### EMPOWERING OUR MEMBER GROUPS THROUGH NATIONAL SUMMITS

*'I have come away from the Summit more informed, and with the ability to forge ahead. The camaraderie amongst the women was truly amazing. It has proved to me that with a common goal in mind, we can do anything.'* – Lyndal, SA (National Summit 2002)

In 2002 and 2006 BCNA held National Member Group Summits in Melbourne and Sydney. Representatives from our Member Groups and key breast cancer advocates attended the summits. These events informed the delegates about BCNA's current initiatives and included workshops to help groups supporting women at a grassroots level. The summits also gave women the opportunity to raise issues of importance from their communities, helping inform our future work.

The feedback received from the participants demonstrated that they had been armed with the latest information and were inspired to continue their important work back in their communities.

*‘Thank you for all the positive and extremely helpful information that you have sent me, on this, the beginning of my journey with breast cancer. I believe: “to gain knowledge is to be empowered”.’ – Coral, NSW*

# 9

## EVERY PICTURE TELLS AN INSPIRING STORY

*‘None of the women like what has happened, none of them pretend it is easy, but all, in their own indomitable way, are inspirational!’ – Maria Prendergast, photographic exhibition coordinator.*

In 2007, we commissioned a select group of experienced photographers to capture a day in the life of 13 women with advanced breast cancer. The women were from all parts of Australia representing a variety of ages, cultures and lifestyles. The beautiful portraits and the stories accompanying each are celebrations of women who see themselves as ‘living with, not dying from’ secondary breast cancer. This moving exhibition has so far been displayed in Brisbane, Melbourne and Adelaide. The portraits exhibition booklet is included in the *Hope & Hurdles* Pack.

# 10

## EMPOWERING PADDLERS

In 1998 at our First National Breast Cancer Conference for Women, Michelle Hanton from the Northern Territory was inspired by Canadian speaker Sharon Batt, to establish a dragon boat team in Australia. After being launched in Darwin, ‘Dragons Abreast’ teams began to appear around Australia.



Michelle approached BCNA to provide funding to enable her to build and strengthen a national program for dragon boating by breast cancer survivors.

Dragons Abreast became a BCNA Project in March 2002 and we were able to provide capacity building funding for a year to assist with Michelle’s travel and administrative costs.

Today, Dragons Abreast has 43 member groups involving some 1600 individuals around the country.

▼ The *Hope & Hurdles* Exhibition on display at the Melbourne launch, 2007.



# To represent

## 1

### ESTABLISHING THE SEAT AT THE TABLE PROGRAM

*'I soon realised that my contribution was not medical – it was practical... In fact I had a lot to offer.'* – Kaye, Qld

In the Australian context consumer representation in health research, policy and service delivery has been long valued, but rarely achieved. BCNA's *Seat at the Table* program is recognised nationally and internationally as a model for other health groups to emulate. The program attracts, recruits, trains, appoints and supports women with breast cancer to actively participate in committees, boards and forums to positively influence their decision-making. The women sit alongside scientists, doctors and academics to ensure the needs of women are considered as a priority. Over the past ten years, breast cancer representatives, supported by BCNA, have contributed to crucial system and program improvements.



Anne Revell (pictured above) from WA, has been a BCNA advocate since 2003. In 2008 she represented BCNA on the Royal Australian & New Zealand College of Radiologists – Quality Use of Diagnostic Imaging (QUDI) Program Management Committee. For her work on the committees she was presented with the College's 'Distinguished QUDI Service Award'.



## 2

### TRAINING WOMEN TO REPRESENT

*'The training has given me more confidence, broadened my skills, understanding and awareness about breast cancer issues and advocacy. It has fanned the "fire in the belly".'* – Steph, SA

Over the past ten years we have trained more than 250 women to represent women with breast cancer at many levels. Our three day Advocacy and Science courses have offered women the knowledge, skills and confidence to sit on medical, scientific and health planning committees. Experts in their respective fields including epidemiologists, geneticists and breast cancer clinicians have volunteered their time and expertise as lecturers. They can see great value in having well-informed women using their energies to drive change and improvements. Our training program has been used as a model for other groups, here and overseas, keen to undertake similar work.

## 3

### WORKING WITH GOVERNMENT

*'I look forward to working with Breast Cancer Network Australia in helping support women diagnosed with breast cancer and to ease the burden of this disease on Australian families.'*  
– Nicola Roxon, Minister for Health and Ageing (February 2008)

Over the last decade BCNA has worked successfully with government to bring about changes that will improve the lives of those affected by breast cancer. In 2008 we saw the implementation of two government schemes which BCNA had successfully advocated.

We were delighted in September 2008 when the Minister for Health and Ageing Nicola Roxon launched a new national external breast prosthesis subsidy program for women. BCNA Community Liaison Kay Ellis was with the Minister when she made her announcement:

*'This will mean a lot to women across Australia. I know it would have made a difference to my mum. She was diagnosed 40 years ago and her doctor gave her a rice bag as her prosthesis. How things have changed.'* – Kay, Qld

Late in 2008 we also saw the implementation of a Medicare rebate for breast MRI screening for women under the age of 50 who are at high risk of breast cancer. We had advocated this important initiative since 2005.

*'Thank you, thank you, thank you!!! to everyone in BCNA and elsewhere who have helped to bring this about for the sake of my daughter and all those who have to walk her path of BRCA2.'* – Jenny, NSW

*'Advocacy doesn't take away the pain, but for me it helped to make it bearable and give my life some meaning.'* – Judy, BCNA Advocate, Vic



▲ Women working together: (L-R) CEOs and Chairs from the National Breast Cancer Foundation Sue Murray and Ros Kelly; from BCNA Patricia Edgar and Lyn Swinburne; and from the National Breast and Ovarian Cancer Centre Helen Zorbas and Megan Keaney.

# 4

## COLLABORATION WITH OUR 'SISTER' BREAST CANCER ORGANISATIONS

Over the last decade BCNA has worked closely with both the National Breast Cancer Foundation (NBCF) and the National Breast and Ovarian Cancer Centre (NBOCC). Each organisation has its distinct niche and focus, and we endeavour to complement each other's work in our aim to achieve the best outcomes for women with breast cancer.

In March 2008, BCNA convened a collaborative meeting between the NBCF, NBOCC and BCNA to discuss ways we can best work together to support each other and, ultimately, reduce the impact of breast cancer on our community.

Both NBOCC and NBCF acknowledge our expertise as the peak national body representing women with breast cancer and their families, and actively seek BCNA's input into their own initiatives. The NBOCC has at least one of our advocates on each of its working parties, project teams and advisory groups. Two BCNA advocates sit on the NBCF's Research Advisory Committee and the NBCF offers progress reports to our representatives at its annual research update.

The NBOCC publication *From the Source* is included with each issue of BCNA's *The Beacon* magazine, ensuring that our members are kept informed about the important work of the NBOCC.

# 5

## ADVOCATING FOR IMPROVED TREATMENTS

*'It's great news [that Herceptin is now available]. It looks like the Prime Minister was listening and Breast Cancer Network Australia has done some great lobbying.'* – Janet, Vic

It is devastating for women to learn that a treatment exists which might save or extend their lives, and yet is financially out of their reach.

In 2001 BCNA led a national campaign to have the drug Herceptin made available to women with HER2+ secondary breast cancer. This product was very expensive – well outside the range of most people, and yet trials had demonstrated significant benefit to many women. Affordable access had been denied as the Pharmaceutical

Benefits Advisory Committee deemed Herceptin not to be cost-effective. We worked in a very committed and strategic way to argue our case to politicians, including directly to the Prime Minister and Health Minister, and to the public via the media. We were delighted when the Federal Government established a special program to ensure free access to women with advanced disease. This program remains in place today.

## Survivors push for cancer drug subsidy



**Public demonstration** for cancer drug subsidy. The demonstration was held in front of the Parliament House in Canberra. The women in the foreground are holding signs that read 'Herceptin is not a luxury drug' and 'Herceptin is not a luxury drug'. The women in the background are holding signs that read 'Herceptin is not a luxury drug' and 'Herceptin is not a luxury drug'. The women in the foreground are holding signs that read 'Herceptin is not a luxury drug' and 'Herceptin is not a luxury drug'. The women in the background are holding signs that read 'Herceptin is not a luxury drug' and 'Herceptin is not a luxury drug'.

In 2006 the issue of Herceptin emerged again following positive results from clinical trials demonstrating the effectiveness of Herceptin in women with HER2+ early breast cancer. Once again, we sprang into action and with the cooperation of many stakeholders and strong relationships forged over years, Herceptin was added to the PBS by the end of that year.

Over the past decade, BCNA has been involved in a number of successful campaigns to ensure women with breast cancer can gain access to the latest treatments. We take pride in being regarded as an advocacy organisation which takes a measured and informed approach, while maintaining our passion for the women we represent.

# To represent



## 6

### CHAMPION WOMEN LEADING THE WAY

*'I know and understand BCNA is a grassroots organisation, although to others it may seem like a big national. It's important we continue to demonstrate BCNA grew because of Lyn and other BC survivors and it's amazing to be a part of the journey.'*  
– Pat, former BCNA NT State Representative

From 1998 to 2007, BCNA had two key representatives in each state and territory. Our State Representatives played an important role in being the 'eyes and ears' of our network across Australia and in representing us in a variety of ways. They have been a symbol that BCNA is a national organisation and, especially in the early days, were instrumental in helping us establish networks across the states in which they were based.

▲ BCNA's State Representatives at our Melbourne Think Tank in 2006.

As BCNA grew, so did the demand on their time and involvement, and it became clear that we needed more community champions. Our State Reps system has now been incorporated into our Community Liaison Program and our champion women continue to play an important voluntary leadership role across the country.

## 7

### WORKING WITH OTHER ORGANISATIONS

*'Both BCNA and beyondblue want to provide quality information and support for women affected by breast cancer and depression – and their families. We hope that through this partnership women will know there are places they can go for help.'*

– beyondblue CEO Leonie Young

BCNA worked collaboratively throughout late 2008 with beyondblue: the national depression initiative to develop a fact sheet for women about depression and breast cancer. It's estimated that up to 50% of all women with breast cancer will experience depression or anxiety and yet there had been little information available for women and their families.

Through this partnership we have drawn on our respective areas of expertise to develop the fact sheet which can be promoted through both our organisations. The joint launch of the fact sheet in December 2008 was very successful with Raelene Boyle from BCNA and Jeff Kennett from beyondblue both speaking. The fact sheet has been very popular with women and health care professionals, with more than 1,000 distributed by BCNA in the first two months.

This process has provided BCNA with a fantastic model for working with other organisations. As a result we are currently developing a fact sheet on breast cancer pathology in partnership with the Royal Australasian College of Pathologists.



This fact sheet was produced by beyondblue: the national depression initiative and Breast Cancer Network Australia.

*'Depression can hit anybody. It doesn't matter how well adjusted you are.'* – Mary, age 62, breast cancer survivor of 13 years

Being diagnosed and living with breast cancer can take its toll not only on your body, but also your mind. Depression in women with breast cancer is common, but is often overlooked and therefore, under-treated.

This fact sheet provides information on depression, its links with breast cancer, available treatments for depression and how to help yourself or someone close to you.

#### WHAT IS DEPRESSION?

*'It wasn't so great if someone had asked "How do you feel emotionally out of 10?" the way they did about physical pain.'*

– Julie, age 52, breast cancer survivor of 10 years

The word depression is sometimes used to refer to sadness or a low mood. However, depression is more than just a low mood – it's a serious illness. It is common to experience a range of emotions and symptoms after a breast cancer diagnosis, including feelings of stress, sadness and anger. However, some people experience these feelings intensely, for long periods of time and often without reason. People with depression find it hard to function every day and may be reluctant to participate in activities they once enjoyed.

#### WHAT IS THE LINK BETWEEN DEPRESSION AND BREAST CANCER?

*'I was just one step on top of the other – the surgery, the chemo, my marriage, the kids, my job, thinking about my mortality – and I just fell into the well.'* – Julie, age 52

Research shows that depression among women with breast cancer is common. One recent study found that up to 50 per cent of women with early breast cancer may experience depression and/or anxiety in the year after diagnosis. It is understood that fewer women experience these conditions in the second, third and fourth years, however up to 15 per cent do.



Photo credit: Breast Cancer Network Australia

women may still experience these conditions in the fifth year after diagnosis. This may be related to a number of different factors.

#### Physical changes

Symptoms of breast cancer treatment such as hair loss and pain can put a person at greater risk of depression. It can also make depression difficult to diagnose as these symptoms can be mistaken for breast cancer. In addition to this, some breast cancer treatments, such as chemotherapy and hormone therapies can cause chemical changes in the brain. This can affect a person's ability to experience depression.

#### Lifestyle changes

When you have breast cancer, there are many changes that you may have to deal with including:

- coming to terms with "Why me?"
- dealing with the uncertainty of the breast and imagining the worst
- dealing with hair loss and the side effects of treatment
- making family, work and financial adjustments in anticipation of treatment and/or periods of being unwell
- dealing with the response of partners, children, family and friends.

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*'Your group should be enormously proud of the way in which it has helped shape and improve health care and outcomes for women with breast cancer.'*

*Laureate Professor Robert Sanson-Fisher, University of Newcastle, NSW*

# 8

## REPRESENTING WOMEN ON CLINICAL TRIALS

*'The Network's support has been critical to the success of the study... I feel their input is invaluable.'*

– Xanthi Coskinas,  
SNAC Trials Coordinator

It is widely accepted that the surgical removal of lymph nodes in a breast cancer patient's armpit can cause problems in the woman's arm, and sometimes the development of a life-long condition called lymphoedema. In May 2001 the Royal Australasian College of Breast Surgeons decided to commence a trial (SNAC1) to consider whether less invasive surgery could be a safe and effective alternative. BCNA jumped at the opportunity to be involved, seeing great value to women if this could be demonstrated.

BCNA Advocate and breast cancer survivor Avis MacPhee was appointed to the trial management committee. Avis worked tirelessly to ensure written information for patients was clear and understandable, that quality-of-life issues were addressed in the trial and that trial progress was reported back to the participants. We helped recruit surgeons and their patients and promoted the trial through BCNA's website.

The trial was extremely successful, with results demonstrating the effectiveness of the sentinel node biopsy procedure, which has now become standard practice for women with small tumours.



# 9

▲ Lyn Swinburne signing the Charter of Paris against Cancer in 2000.

## REPRESENTING AUSTRALIAN WOMEN IN THE INTERNATIONAL ARENA

In February 2000, our CEO Lyn Swinburne was one of three Australians invited to attend the Global Cancer Summit in Paris and to be a signatory to the Charter of Paris against Cancer. Lyn was invited as a representative of Australian cancer patients. This was the first of many opportunities for BCNA to represent Australians affected by breast cancer in the international arena.

In 2008, the Australian Embassy in Berlin held a reception on behalf of BCNA in conjunction with the European Breast Cancer Conference. Guests included leading Australian and international oncologists and organisation leaders. This was an excellent opportunity to highlight BCNA's work and our approach of working in partnership on a global scale.

# 10

## EDUCATING THE DOCTORS OF TOMORROW

*'I really enjoyed speaking to the students, they really listened and asked a lot of questions. I think BCNA has made a contribution to better doctor/patient relationships in the future.'*

– Vera, Vic



In 2005 BCNA formed a partnership with the University of Melbourne which has involved women from BCNA in the university's teaching program for third year medical students. Our women have been able to share their personal experiences of breast cancer in workshop sessions with doctors of the future, highlighting among other aspects the need for effective communication between doctors and their patients.

*'I gained a good sense of the emotional aspects of things and what patients did/did not like about the way doctors/nurses handled her situation. Very helpful.'* – Medical Student

# To link together

## 1

### LINKING WOMEN AT NATIONAL CONFERENCES



▲ Delegates at our first National Breast Cancer Conference for Women in 1998.

The inaugural National Breast Cancer Conference for Women held in October 1998 in Canberra, was the first opportunity for women across Australia to come together and address issues of concern for people affected by breast cancer. The recommendations and strategies suggested by women were compiled into the *Making a Difference* report. BCNA was officially launched at the end of this conference and used the report's recommendations to drive its national advocacy efforts.

In 2004 BCNA held the second National Breast Cancer Conference for Women in Melbourne. Over 600 breast cancer survivors from across Australia came together to consider progress, to highlight issues and identify a new set of recommendations for change. The conference delegates, linked together via their own personal experiences and a commitment to help others, used their combined voice to form the basis for the *Still Making a Difference* report. Its recommendations have continued to inform BCNA's work.



## 2

### PINK LADY SILHOUETTES LINK TOGETHER TO MAKE A POWERFUL STATEMENT

*'Our first Mini-Field was a roaring success. It was moving but at the same time a lot of fun to run. Many women put their names down to become involved in our newly formed breast cancer support group.'* – Margaret, Qld

In 1998, our first *Field of Women*, held on the lawns of Parliament House in Canberra, marked the launch of BCNA. The *Field* consisted of 10,000 Pink Lady silhouettes representing the women diagnosed with breast cancer that year and 2,500 white silhouettes for the women who would die from breast cancer in 1998. The *Field of Women* silhouettes sent a powerful visual message across Australia that women with breast cancer could link together to form a strong movement – Breast Cancer Network Australia – which would work to bring about better outcomes for women and their families. Since our 1998 launch a *Field of Women*, incorporating pink, white and blue silhouettes (for the men diagnosed) carrying personal messages, has been held in each state.

BCNA's Pink Lady logo reflects our key focus – on the woman rather than the disease, and our *Field of Women* events have been a way to link women and the community together to pay tribute to and support those Australians affected by breast cancer.

▲ Our first *Field of Women* outside Parliament House in Canberra, 1998.

Since 2001 communities across Australia have further embraced our Pink Lady by holding 740 *Mini-Fields*, each consisting of 100 silhouettes in a community-based display. See page 24 for the list of *Mini-Fields* held in 2008.

## 3

### OUR MEMBER GROUPS LINK TOGETHER IN OUR NETWORK

*'BCNA makes us feel part of something bigger. In our community we are the Pink Lady – like so many other groups around Australia.'* – Margaret, SA

At the end of 2008 we had 185 Member Groups and 17 Associate Member Groups as part of the BCNA network. The vast majority of our Member Groups operate as community-based support groups offering practical help and assistance to women diagnosed with breast cancer within their local area. Our Member Groups help promote our free resources such as the *My Journey Kit* and *The Beacon* in their communities and help to inform our work.

In 2002 and 2006 BCNA hosted Member Group Summits in Melbourne and Sydney, which brought together representatives from each of our groups, encouraging the sharing of information and identifying strategies to help women in need.

*'As I raised my arms at Lyn Swinburne's request, I saw that I was not alone and there are thousands of women just like me.'*

*– Sue, Participant in the Field of Women LIVE at the MCG*

# 4

## LENDING A HAND TO OTHER ADVOCATES AND GROUPS

*'It is a fitting tribute to all the great achievements of BCNA on its tenth anniversary that we have achieved Step by Step using the excellent model that you guys created in the My Journey Kit and then generously shared across the ditch.'*

– Libby Burgess, Chair, Breast Cancer Aotearoa Coalition, New Zealand

BCNA is committed to playing a leading role in helping other breast cancer organisations around the world. We have shared many of our programs and resources, with organisations in Hong Kong, Taiwan, the UK and New Zealand, developing versions of our *My Journey Kit* and *Hope & Hurdles Pack* for use by women in their respective countries.

In 2007, our CEO Lyn Swinburne was the keynote speaker in Tokyo at the National Conference to announce the formation of the Japanese Breast Cancer Network, based on the model of BCNA.

Lyn has been a guest speaker at several international meetings. In 2007 she chaired the Second World Summit for Breast Cancer Advocates, held in Stresa, Italy.

# 5

## LINKING TOGETHER THE COMMUNITY IN A MASS DISPLAY OF POWER AND SUPPORT

*'The Field of Women has achieved a goal many business and government bodies would envy: it has united the AFL, the Melbourne Cricket Club, the MCG, the 16 AFL clubs, football supporters and sponsor groups, women's groups, school and tertiary students, politicians, community leaders, and health professionals.'* – Corrie Perkin, Journalist, *The Age*, 30 April 2005

▼ An aerial view of the Sydney Field of Women LIVE 2007.

Our Pink Lady came to life with extraordinary community involvement when we presented our *Field of Women LIVE* events at the Melbourne Cricket Ground (2005) and Sydney's Telstra Dome (2007). 13,000 people stood together in pink and blue ponchos to represent the women and men diagnosed each year with breast cancer. *Field of Women LIVE* thrust BCNA into the national and international media and touched the lives and hearts of all who experienced this extraordinary spectacle.

In 2008 we launched our *Field of Women* website, [www.fieldofwomen.org.au](http://www.fieldofwomen.org.au). The site enables friends and family to send messages of support to loved ones who have been diagnosed with breast cancer, no matter where they live.



▲ *Resilience* is a free resource kit for women diagnosed with ovarian cancer produced by Ovarian Cancer Australia, based on our *My Journey Kit*.

# To link together

## 6

### LINKING THE PINK LADY TO OTHERS AROUND THE WORLD

*'The Field of Women LIVE video is so powerful and no matter how many times I watch I can't help but be moved by it. I want others in England to have the chance to see what you have created. I am sure they would also be moved by the powerful message it gives and would also inspire and give hope to those affected by breast cancer.'*

– Tom Southern, Linda McCartney Centre, Coordinator of the 2008 *Field of Women LIVE* Liverpool, UK

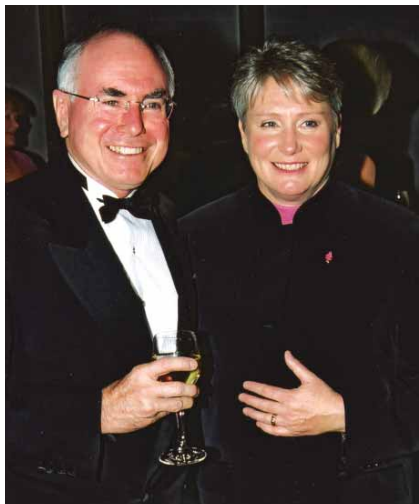
Our Pink Lady logo has not only linked women together in Australia but has been adopted as a powerful symbol in other countries. The Scottish Breast Cancer Campaign has taken up our Pink Lady and added a kilt! Every year in Cyprus, the women from the Europa Donna Cyprus group plant pink silhouettes in a prominent part of that country, as part of a ceremony to communicate important messages to the women of Cyprus. 2008 saw the first international *Field of Women LIVE* take place in Liverpool UK.

▼ Stella McCartney wears BCNA's Pink Lady badge proudly as the patron of *Field of Women LIVE* Liverpool 2008.

## 7

### LINKING TOGETHER WITH INFLUENTIAL INDIVIDUALS

Former Prime Minister John Howard was one of the 1,100 people who helped celebrate Raelene Boyle's 50th birthday in June 2001. The evening raised \$350,000 for BCNA's core activities and helped establish the BCNA 2002 Community Grants Program. The evening also brought together leaders in government, business and the health sector, providing BCNA with the opportunity to highlight our important messages.



## 8

▲ BCNA staff speaking to nurses at the Breast Care Nurses conference.

### LINKING TOGETHER WITH BREAST CARE NURSES

*'Many thanks for all you do for us to assist the many women we see affected by breast cancer.'*

*'We couldn't do it without you!'*

– Kerry, Breast Care Nurse

Improving women's access to breast care nurses was the number one priority identified by women attending our 1998 and 2004 National Conferences for Women with Breast Cancer.

We recognise that nurses are a most crucial link between BCNA and women in their care. We have fostered strong and long-standing partnerships with more than 500 breast care nurses across Australia. We have included them in the development of our information resources, presented at their conferences, undertaken surveys requesting their feedback on our services and helped promote their role to hospitals and the community.

Nurses have placed orders for over 28,000 *My Care Kit* bras for women since 2005, and sixty-eight percent of women who ordered *My Journey Kits* in 2008 heard about the Kit from their nurse.



*'My biggest issue is isolation. I need to hear from other women who are in the same situation. It was great to meet other women in my position at the forum.'* – Jane, NSW



▲ Asking a question at a BCNA Forum in Melbourne 2008.

# 9

## LINKING WOMEN TOGETHER AT BCNA FORUMS

*'Many thanks for such an informative and relaxed afternoon on Saturday. The forum provided a wonderful opportunity to meet other women and a chance to link in with one another'* – Jenny, Vic

Since 2002, BCNA has held information forums for women diagnosed with breast cancer in each state and territory. The forums feature guest speakers including leading health professionals. They are also an important means by which we can promote BCNA activities, report on progress and link our members together. We always ensure that there is sufficient time at the forums for women to meet and share stories over a cuppa.

In 2008 we held five information forums for women – four in NSW, one in Queensland and one in Victoria.

# 10

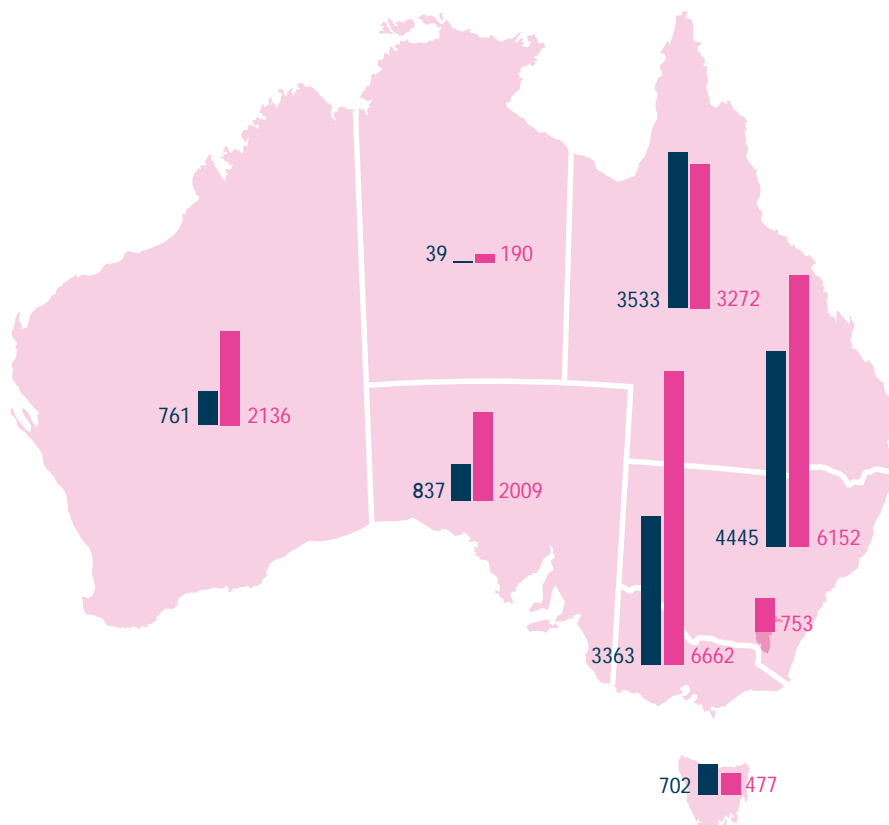
## LINKING WOMEN TO BCNA FROM ALL PARTS OF AUSTRALIA

*'Thank you for your vision and generosity of spirit, for linking us all together and for lessening the sense of isolation and fear...it sometimes feels a little lonely out in the provinces!'* Mary, Qld

Our members come from all parts of the country – from major cities, regional centres to remote homesteads.

### BCNA membership numbers – state and territory breakdown

- Country
- Metro



# Key partners and sponsors

## MAJOR PARTNER



*100% goes into our pink buns.  
(Because 100% goes to  
Breast Cancer Network Australia.)*



◀ Roger and Lesley Gillespie, Co-Founders of Bakers Delight, planting a silhouette at a BCNA Mini-Field of Women in 2008.

## *Bakers Delight*

Bakers Delight is BCNA's major partner and has been supporting the organisation since 2000. Its incredible support is a genuine and long-term commitment that ensures all levels of Bakers Delight are involved in the partnership, from franchisees and their bakery staff to Regional offices and head office, to their Board of Directors.

Since 2000, Bakers Delight has raised more than \$2.7 million for BCNA, primarily through its annual in-store 'Pink Bun' promotion. The 2008 campaign raised over \$680,000.

Bakers Delight provides BCNA with a fully equipped and serviced rent-free national office, offers us strategic advice and provides access to its networks.



## SUPPORTING PARTNERS



### Sussan

Sussan has been selling BCNA merchandise in its 273 stores across Australia since 2006. This partnership not only raises much needed funds for BCNA but it also provides an excellent promotional tool, to ensure women in local communities know to contact BCNA if they or someone close to them is diagnosed with breast cancer. In 2008, through the Sussan Fun Run, the Victorian community raised over \$60,000.

**sussan**

### Australia Post

Australia Post has been a supporter of BCNA since 2001. Australia Post sponsors the national *Mini-Field of Women* project and distributes the *My Journey Kit* and *Hope & Hurdles Packs* free of charge to women throughout Australia.



▼ Australia Post staff at *Field of Women LIVE* Sydney in 2007.



▲ Naomi Milgrom Executive Chair and CEO, Sussan Group with Lyn Swinburne, Patricia Edgar and Raelene Boyle at *Field of Women LIVE* Sydney in 2007.

### Pacific Brands

Pacific Brands and BCNA formed a partnership to provide Berlei post-surgery bras in the *My Care Kits* to women who have had breast cancer surgery. This successful program has developed to now reach more than 7,500 women every year.

The Pacific Brands partnership was extended in 2008, to ensure BCNA could reach more Australians through Forums and Community Liaison training programs.

**PACIFIC BRANDS**

▼ Julie Hassard (BCNA), Sally Berkeley (Berlei), Katie Nicholson (BCNA) and Jane Edser (Berlei) with the cheque from the Berlei Pink Bra Campaign 2008.



## SPONSORS

### *Ernst & Young, Freehills, Multiwall, Naughtons Transport, PaperlinX and Vega Press*

Thanks also to our sponsors – Ernst & Young for providing pro bono auditing services and advice, Freehills for giving pro bono legal advice, Multiwall for supplying storage free of charge, Naughtons Transport for storing our pink silhouettes, PaperlinX for providing paper for *The Beacon* and Vega Press who print our annual report, *The Beacon* and *The Inside Story*.

### Australian Government

The Australian Government provided initial support for the development and launch of our *My Journey Kit* in 2004. Its subsequent four-year funding agreement that contributed to *My Journey Kit* reprinting and distribution costs was due to expire in June 2009. Negotiations in 2008 resulted in a further three-year funding commitment, which will enable us to continue distributing *My Journey Kits* to newly diagnosed women, and *Hope & Hurdles Packs* to women living with secondary breast cancer.



**Australian Government**

## Executive team

## Fundraising 2008



▲ Lyn Swinburne with Professor Russel Kenley, Director, Australian Graduate School of Entrepreneurship (AGSE).

BCNA as an organisation has grown from two staff in 1999 to employing 24 staff at the end of 2008. The staff at BCNA have always been committed to achieving high-quality outcomes for women and their families affected by breast cancer across Australia.

Over the last ten years BCNA has been led by our Chief Executive Officer and breast cancer survivor Lyn Swinburne, AM. During this time Lyn's passion and dedication for growing BCNA as an organisation has been recognised with a number of business and community awards including:

- Induction into Swinburne University of Technology's Australian Graduate School of Entrepreneurship Hall of Fame, July 2008
- 2007 Melburnian of Year, August 2007
- Order of Australia (AM), January 2006;
- Finalist in the Australian of the Year 2006;
- Tattersall's Award for Enterprise and Achievement 2005;
- Equity Trustees' Not-for-Profit CEO of the Year Award 2004-2005;
- The Centenary Federation Medal, 2003;
- Induction onto the Victorian Women's Honour Roll, 2002; and
- Victorian Telstra Business Woman of the Year in the Community and Government category, 2001.

In 2008, the senior management team included:

**Julie Hassard** – National Policy and Programs Manager

**Kirsten Pilatti** – National Communications and Marketing Manager

**Damien Arnold** – Finance and Resource Manager

**Natalie Rolfe-Stuart** – Human Resources Manager.

Members, friends and community groups continued to enthusiastically give their support to BCNA during 2008, holding over 170 Pink Lady fundraising events. Others have generously donated their time and money to support us. Thank you to everyone who contributed – your support continues to make our work possible.

We appreciate all your contributions. Special thanks to those who contributed more than \$5,000 to BCNA in 2008:

- Aitken Partners – Vic
- Champagne Canapés and Cupcakes – Judd Farris Recruitment – NSW
- Cocktail Party – Gillian Walker – Vic
- Cocktail Party – Joh Bailey, Dorothy Fletcher and Sandra Smorgon – NSW
- Cocktail Party – Roth Charitable Foundation – John Roth – NSW
- Coles Group – Vic
- Concert for a Cure – Nicholas Vindin – NSW
- Dunlop Flooring
- Elspeth Davey – Qld
- G-Force – Vic
- Gillian Franklin – Vic
- Girls Night Out – Vera Kostovski – Vic
- Langhams Luncheon – Richmond Assembly of God – Mary Crickett – Vic
- Manildra Group
- MFOW 2008 – Maree Roberts – NSW
- National Australia Bank Ltd – Vic
- Peter McInnes Pty Ltd – NSW
- Pink Breakfast – Trudy Harris – NSW
- Pink Dinner – Brighton Grammar School – Vic
- Pink Ladies Golf Days – Vic
- Pink Lady Art Exhibition – Lisa Seward and Rachel West – Vic
- Pink Lady Luncheon – University of Southern Queensland – Liz Newberry – Qld
- Ritchies
- Robert Boysow
- Round the Bay – Michael Sowards – Vic
- Rural Press Ltd – NSW
- Sue Morphet – Vic
- Tesselaar Tulip Festival – Vic
- The Pratt Foundation
- Tontine – Vic
- Trivia Night – Terrance Tearooms – Vic
- VSI Pty Ltd – Ian Drysdale
- Wade in the Water – Linette Etheredge
- Woollahra Golf Day – Dallas Griffin – NSW
- Women are Glamorous – Maria Gomes – NSW
- Yarra Bend Ladies Golf Club – Vic

### WORKPLACE GIVING

We also thank the organisations which have invited BCNA to be part of their workplace giving program. In 2008 staff from **Aviva, BHP Billiton, Coles Group, NAB, Macquarie Group** and **Sussan** generously supported BCNA through these programs.



# Financial summary

	2007*	2008*
<b>Income</b>		
Events	148,581	153,223
<i>Field of Women LIVE</i>	940,000	-
Community Fundraising	481,118	644,402
General Donations	341,500	405,257
Sponsorship	667,055	1,036,365
Government funding	204,000	308,000
Bank interest	78,127	121,630
<b>Total</b>	<b>2,860,381</b>	<b>2,668,877</b>
<b>Expenses</b>		
Program and Services	1,644,167	1,803,164
General Operations	263,626	352,190
Events	85,259	201,765
<i>Field of Women LIVE</i>	380,000	
Community Fundraising	157,702	289,206
<b>Total</b>	<b>2,530,754</b>	<b>2,646,325</b>
<b>Surplus</b>	<b>329,627</b>	<b>22,552</b>

\* For year ended 31st December

BCNA achieved another strong financial result in 2008. Excluding the effect of the *Field of Women LIVE* 2007 event, our overall revenue grew by 39% in 2008. This growth was a result of an increase in sponsorship and general donations.

We receive a contribution towards the costs of the *My Journey Kit* and *Hope & Hurdles Pack* from the Commonwealth Department of Health and Ageing. The variation in government funding over the last two years is due to timing differences in receipt of the funds only.

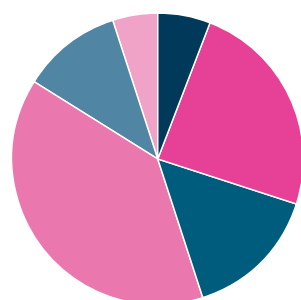
The 2007 surplus and the solid income generation of 2008, has allowed us to increase our expenditure in our programs and services by 10%.

We have continued to contain our expenses in the fundraising area ensuring an increasing return on investment. Our community fundraising activities not only provided financial benefits but also allowed BCNA to build community awareness on the services available for Australians affected by breast cancer.

General operations expenses remain extremely low through the assistance of our partnership with Bakers Delight.

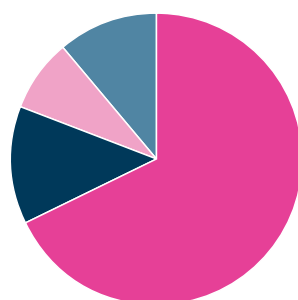
BCNA is committed to maintaining a strong financial base to ensure that all Australians affected by breast cancer can access quality information and support, free of charge.

BCNA's income 2008



- Events – 6%
- Community Fundraising – 24%
- General Donations – 15%
- Sponsorship – 39%
- Government Funding – 11%
- Bank Interest – 5%

BCNA's expenses 2008



- Program and Services – 68%
- General Operations – 13%
- Events – 8%
- Community Fundraising – 11%

# Mini-Field locations 2008

In 2008 we had **168** *Mini-Field of Women* events held around Australia. They were a wonderful mixture of setting and style reflecting local communities. From lunches in private homes, morning teas in workplaces, barbecues in public parks and silent walks in gardens to static displays in shopping centres and farmers markets.

## ACT

Bruce  
Yarralumla

## NSW

Armidale  
Batemans Bay  
Bathurst  
Bellawongarah  
Byron Bay  
Chullora  
Clarence Town  
Coffs Harbour  
Cooma  
Cowra  
Darlinghurst  
Dubbo  
Forbes  
Gosford  
Gurley

Kahibah  
Katoomba  
Killarney Vale  
Kingscliff  
Lake Munmorah  
Laurieton  
Manning Park  
Mosman  
Nelson Bay  
Newcastle  
Nimbin  
Northbridge  
Port Macquarie  
San Remo  
Springfield  
Sussex Inlet  
Sydney  
Tallwoods Village  
Tamworth  
Tuncurry

Tweed Heads  
Umina Beach  
Wagga Wagga  
Wahroonga  
Woollahra

## QLD

Arundel  
Aspley  
Ayr  
Bribie Island  
Bundaberg  
Cairns  
Cleveland  
Gayndah  
Goondiwindi  
Grasstree Beach  
Gympie  
Ipswich  
Kilcoy  
Lawn Hill  
Logan Village  
Manly West  
Maryborough  
Morayfield  
Mt Isa  
Pialba  
Redcliffe  
St George  
Tambo  
Toowoomba  
Townsville  
Virginia  
Willowbank

## SA

Aberfoyle Park  
Adelaide  
Beverley  
Coonalpyn  
Kadina  
Kingscote  
Mt Barker  
Mt Osmond  
Noarlunga  
Port Pirie  
Somerton Park  
Victor Harbor  
West Lakes  
Whyalla Norrie

## TAS

Beaconsfield  
Burnie  
Deloraine  
Devonport  
Hobart  
Launceston  
New Norfolk  
Wesley Vale  
Wynyard

## VIC

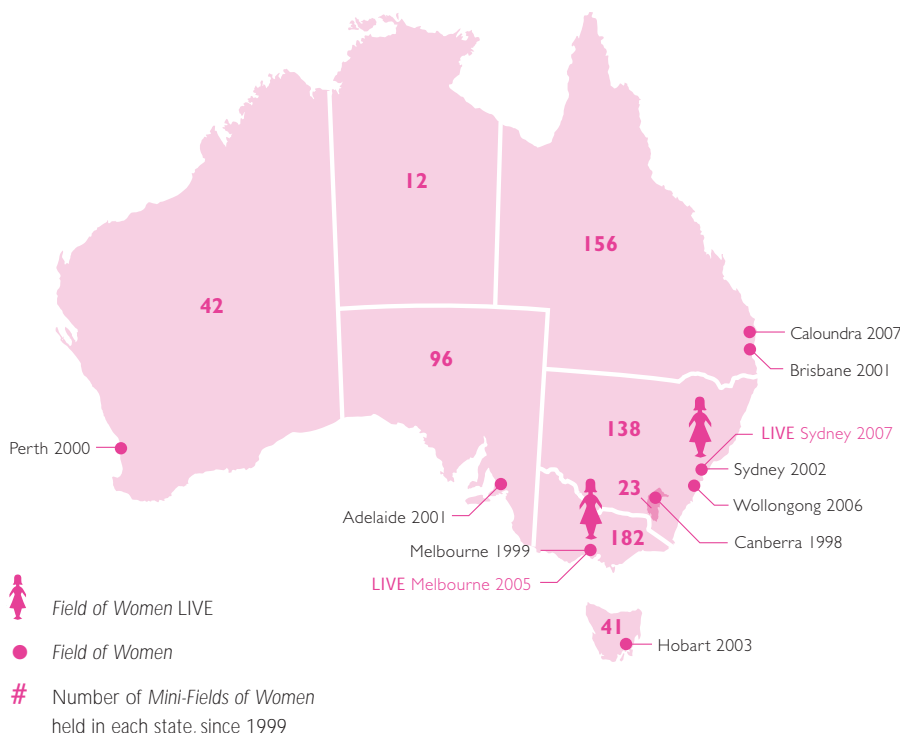
Ballarat  
Benalla  
Burwood  
Camberwell  
Camperdown  
Caulfield South  
Cobram  
Cohuna  
Dandenong North  
Doncaster East  
East Geelong  
East Melbourne  
East Ringwood  
Epping  
Frankston  
Glen Iris  
Glen Waverley  
Greendale  
Hoppers Crossing  
Keysborough  
Knoxfield  
Kyabram  
Lancefield  
Langwarrin  
Leongatha  
Mandurang

Mansfield  
Melbourne  
Melton  
Mildura  
Mornington  
Mt Waverley  
Mulgrave  
Preston  
Richmond  
Ringwood East  
Sale  
Sanctuary Lakes  
Scoresby  
Shepparton  
Sorrento  
Swan Hill  
Traralgon West  
Vermont South  
Wandin North  
Wantirna  
Warragul  
Watsonia North  
Wonga Park  
Wonthaggi  
Yarram

## WA

Albany  
Bassendean  
Bickley  
Geraldton  
Guildford  
Henley Brook  
Inglewood  
Kalbarri  
West Perth

## FIELD OF WOMEN LOCATIONS SINCE 1999



# Resources

## FACT SHEETS

The following BCNA fact sheets are available:

- Clinical trials
- Depression and breast cancer
- Family history and hereditary breast cancer
- Hair loss
- Summary of patient assisted travel schemes (PATS) across states and territories
- Travel insurance – 1 early breast cancer
- Travel insurance – 2 secondary breast cancer
- Travel insurance – 3 making a complaint
- Travel tips for reducing your risk of lymphoedema
- Tax free superannuation payments for people with a terminal illness



## BROCHURES

We have produced the following free resources to assist people personally affected by breast cancer.

- *Messages of hope and inspiration*
- *Reducing your risk of lymphoedema*
- *Helping a friend or colleague with breast cancer*
- *Messages of hope and inspiration from women living with advanced breast cancer*
- *She has secondary breast cancer – how can I support her?*



Our free brochures and fact sheets can be ordered via our website [www.bcna.org.au](http://www.bcna.org.au) or by calling 1800 500 258 (freecall).

# Endorsements



The *My Journey Kit* has been endorsed by the following organisations:

- Cancer Nurses Society of Australia
- Royal College of Nursing, Australia
- Medical Oncology Group of Australia
- The Royal Australian and New Zealand College of Radiologists
- The Royal Australian College of General Practitioners
- The Royal Australasian College of Surgeons
- The Royal College of Pathologists of Australasia



The *Hope & Hurdles Pack* has been endorsed by the following organisations:

- Cancer Nurses Society of Australia
- Medical Oncology Group of Australia
- Palliative Care Australia
- The Royal Australian and New Zealand College of Radiologists
- The Royal Australasian College of Surgeons
- The Royal College of Pathologists of Australasia
- The Royal Australian College of General Practitioners
- Oncology Social Workers Group of Australia

# 2008 BCNA Advocate appointments

In 2008 our trained Advocates continued to be involved in a variety of committees, working groups and advisory groups at a local, national and international level. This is a summary of our Advocate appointments for 2008.

Organisation	Activity	BCNA Advocate
Australasian Society for Breast Disease Ltd	Member of Executive Committee	Julia Leeds, Qld
Australian Breast Cancer Family Study (ABCFS)	Member of Project Committee	Gerda Evans, Vic
Australasian Lymphology Association	Member of Council for Australasian Lymphology Association	Anna Wellings Booth, ACT
Breast Cancer Genetics Group School of Medicine, University of Adelaide	Member of Research Project Advisory Committee	Nicole Edwards, SA
Breast Cancer Tissue Bank	Member of Advisory Committee	Bronwyn Wells, NSW
Breast Cancer Treatment Group, ACT Health	Member of Reference Committee	Geraldine Robertson, ACT
BreastScreen ACT (ACT and South Eastern NSW)	Members of Regional Advisory Committee	Elspeth Humphries, ACT Anna Wellings Booth, ACT
Cancer Australia	Member National Breast Cancer Foundation/BreastScreen Australia Project Advisory Group	Margaret Tassell, Tas
Department of Health and Ageing (DoHA)	Member of Digital Mammography Accreditation Standards Working Group	Margaret Tassell, Tas
Eastern Health, VIC	Member of Lymphoedema Working Party	Diane Cole, Vic
Kathleen Cuninghame Foundation Consortium for Research into Familial Breast Cancer (kConFab)	Member of Scientific Advisory Board	Janet Green, NSW
Kathleen Cuninghame Foundation Consortium for Research into Familial Breast Cancer (kConFab)	Member of the Executive Committee, Member of Ethics Reference Group	Gerda Evans, Vic
Medical & Scientific Advisory Committee (MSAC)	Member of Committee Reviewing Reference 38 ISH testing for HER-2/neu breast cancer	Pamela Williams, Vic
Medical & Scientific Advisory Committee (MSAC)	Member of the Medical Safety Advisory Committee Advisory Panel reviewing reference 35e PET for myocardial viability, breast cancer and cervical cancer	Roslyn Lawson, Tas
Medicines Australia	Member of the Code of Conduct Appeals Committee.	Judith Maher, NSW
National Breast and Ovarian Cancer Centre (NBOCC)	Member of Steering Committee exploring shared care model of follow-up after breast cancer (phase one).	Lyn Swinburne, Vic
NBOCC	Members of Implementation Advisory Group	Julie Hassard, Vic Suzanne Mullen, NSW
NBOCC	Member of Information Advisory Group	Catherine Nolan, Vic
NBOCC	Member of Data Advisory Group	Susan Timbs, Vic
NBOCC	Members of Advisory Group for the revision and update of the <i>Guide for women with secondary breast cancer</i>	Jennifer Muller, Vic Maria Waters, WA
NBOCC	Member of the 'Modelling of Metastatic Breast Cancer' Advisory Committee	Julie Hassard, Vic
NBOCC	Members of Post Surgical Care of Women with Breast Cancer Project Working Group	Bronwyn Wells, NSW Vicki Shepherd, Qld Julie Hassard, Vic
NBOCC	Member of Advisory Group for the review of the Evidence-base Guidelines for Breast Cancer Follow-up care	Vivienne Luke, TAS.

Organisation	Activity	BCNA Advocate
NBOCC	Member of Multidisciplinary Steering Committee of the Secondary Lymphoedema Project	Anne Holmes, Vic
NBOCC	Member of Survivorship Issues Advisory Group	Lynn King, SA Angela Verde, Vic
NBOCC	Member of the Clinical Practice Guidelines for the Management of Advanced Breast Cancer Committee – Endocrine Therapy Subgroup	Denice Bassanelli, SA
NBOCC	Member of the Clinical Practice Guidelines for the Management of Advanced Breast Cancer Committee – Chemotherapy Subgroup	Jennifer Muller, Vic
NBOCC	Member of the Clinical Practice Guidelines for the Management of Early Breast Cancer (2nd ed.) Review Working Group	Leanne Pentland, Vic
NBOCC	Member of Clinical Practice Guidelines for the Management of Advanced Breast Cancer Committee	Ann Town, NSW
NBOCC	Member of Advisory Committee for the revision and update of the <i>Guide for women with early breast cancer</i>	Leanne Pentland, Vic
National Breast Cancer Foundation (NBCF)	Members of the Research Advisory Committee	Roslyn Lawson, Tas Maryanne Maher, NSW
National Health and Medical Research Council (NHMRC)	Member of Commercialisation of Human Tissue Ethics Committee	Avis Macphee, Vic
National Prescribing Service (NPS)	Member of Research & Development Working Party	Hadas Haileselassie, ACT
National Institutes of Health/National Cancer Institute (USA)	Member of the Breast Cancer Family Registries Steering Committee	Gerda Evans, Vic
National Institutes of Health/National Cancer Institute (USA)	Member of Breast Cancer Family Registries Behaviour Group and Follow-Up Group	Gerda Evans, Vic
North Eastern Metropolitan Integrated Cancer Services, VIC (NEMICS)	Member of the Breast Tumour Group	Susan Crawshaw, Vic
Peter MacCallum Cancer Centre	Member of Survey Development Group Models of Care for Women with Advanced Breast Cancer Project	Jennifer Muller, Vic
Prince of Wales Hospital, NSW	Member of Treatment Focussed Genetic Testing Research Project Committee	Kylie Behr, Vic
RANZCR	Member of Quality Use of Diagnostic Imaging (QUDI) Advisory Group	Ann Revell, WA
RANZCR	Member of Curriculum Advisory Committee	Pamela Bell, NSW
Royal Australasian College of Surgeons	Member of SNAC2 Trial Management and Executive Committee	Avis Macphee, Vic
Royal Australian and New Zealand College of Radiologists (RANZCR)	Member of Standards Liaison Panel	Roslyn Lawson, Tas
Royal Women's Hospital and Royal Melbourne Hospital	Member of Integrated Services Committee	Heather Beanland, Vic
Southern Health Breast Services, Vic	Member of Consumer Reference Group	Pamela Williams, Vic
Southern Melbourne Integrated Cancer Service, Vic	Member of Service Development Group	Pamela Williams, Vic
The Cancer Council New South Wales	Genetic Testing Workshop Attendee	Heather Drum, Vic

Continued on the following page.

# 2008 BCNA Advocate appointments

Organisation	Activity	BCNA Advocate
The Cancer Council Victoria	Member of the Research Group for the peer support telephone support program for women diagnosed with the BRCA1/2 gene mutation.	Deborah Sandler, Vic
The Cancer Council Victoria	Member of the Advisory Group for the telephone support program for women diagnosed with the BRCA1/2 gene mutation.	Kerri Guy, Vic Deborah Sandler, Vic
The Royal College of Pathologists of Australasia	Member of Lay Advisory Committee	Heather Drum, Vic
The Royal Australasian College of Surgeons	Member of the Clinical Advisory Group of the National Breast Cancer Audit	Lyn Swinburne, Vic
The University of Melbourne	Associate Investigator for the <i>Genetic Testing to reduce breast cancer Morbidity and Mortality research project</i>	Gerda Evans, Vic
Therapeutic Goods Administration (TGA)	Member of the Therapeutic Goods Advertising Code Council	Geraldine Robertson, ACT
Therapeutic Goods Administration (TGA)	Member of Complementary Medicines Implementation Reference Group	Geraldine Robertson, ACT
Therapeutic Goods Administration (TGA)	Member of the Advertising Code Council of the Therapeutic Goods Association	Judith Maher, NSW
Victorian Cooperative Oncology Group	Member of the Breast Cancer Committee	Lyn Swinburne, Vic
Women and Children's Hospital, SA	Member of Steering Committee for the MAWSON Database Project, to develop consistent interpretation of BRCA variants across Australia.	Janet Green, NSW





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