



# The Face of BCNA

*Breast Cancer Network Australia* ANNUAL REVIEW 2010

Breast Cancer Network Australia  
ANNUAL REVIEW 2010

- 1 Our vision
- 1 Our mission
- 2 Letter from the Chair
- 4 Our board
- 5 Our patron
- 6 The year in review
- 9 Our members
- 13 Our services
- 19 Our voice
- 22 Our relationships
- 25 Our profile
- 28 Our finances
- 29 Our organisation

Thank you to Australian Paper,  
Designgrant and Vega Press for their  
contributions to this publication.

Photo credits:

p1, 8, 11, 23, 24 Mark Chew

p7 Jeremy Heffernan

p18 Brian Gilkes  
(Courtesy of the Victorian Breast  
Cancer Research Consortium)

p25 Herald Sun



Faces of BCNA:  
Elizabeth, Genie,  
Marg and Judy are  
BCNA members  
and volunteers.  
They are part of our  
network of women  
supporting others.

## Our 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.

## Our mission

BCNA informs, empowers, represents and links together people affected by breast cancer.

*Inform* — we provide quality, up-to-date information about breast cancer, its treatment and services.

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

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

*Link together* — we bring together those who have themselves experienced breast cancer and link individuals and groups sharing similar issues and experiences.

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



---

## Letter from the Chair

---

*These days it can be difficult to imagine a time when people did not talk openly about breast cancer. A time when women were ashamed or embarrassed about their diagnosis. When they were treated like a number and not like an individual. When they were subjected to radical surgery and given little information and even less support. When they held little hope for a future.*

Breast Cancer Network Australia (BCNA) began during this time, and was born out of the desire of one woman to get people to start talking openly about breast cancer. Our founder and CEO Lyn Swinburne had herself experienced the lack of understanding and empathy by the medical profession and the community, and wanted to ensure that all women – no matter who they were or where they lived – would receive the very best treatment and care possible.

Since 1998 BCNA has been the voice for people affected by breast cancer. We help bring people together, provide free information and support, connect communities, influence research and advocate for change. We work to not only make a difference, but to make positive, tangible and practical improvements that directly benefit the individual and those around her.

By the end of 2010 BCNA has developed an engaged network of more than 50,000 strong, informed, influential, focused and very vocal women and men who strive to make the breast cancer journey an easier one. Of the four main breast cancer organisations in Australia, BCNA is the only one that works solely to support the woman and those around her.

Breast cancer, with its signature pink branding, now has a remarkably high, and some would say enviable, profile. Survival rates for women have improved, public understanding and awareness has increased, and the information age has given individuals more knowledge, access and confidence to be involved in their own treatment and care.

We have made considerable progress and we are incredibly proud of our achievements along the way. However, high numbers of women continue to be diagnosed with breast cancer each year. Around 14,000 women will be diagnosed this year alone. Each day seven women will die from the disease. There is still much we need to do.

It is important that we continue to strive for improvements not only for women but for the people around her whose lives are also dramatically impacted by this disease. And, with more women surviving, it is essential that we direct our efforts towards helping women live well beyond breast cancer.

To those who have supported us over the last 12 years, thank you. I invite you to see some of the faces behind the statistics and to read the personal stories our women have shared. With your enduring support, BCNA will ensure their voices continue to be heard.

Marg O'Donnell  
Chair



## Our board



*Marg O'Donnell (Chair)*

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



*Andrew Barling*

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



*Terry Bracks (Deputy Chair)*

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



*Fran Boyle, AM*

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



*Raelene Boyle, AM MBE*

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



*Ron Dewhurst*

Ron has worked in investment management and investment banking for more than 30 years. He is currently Head of Global Investment Managers and Senior Executive Vice President at Legg Mason Inc. He was formerly Head of Americas for JPMorgan Fleming Asset Management and served as Group Chief Executive Officer of IOOF Holdings Ltd. Ron is also on the Board of Trustees of the National Gallery of Victoria.



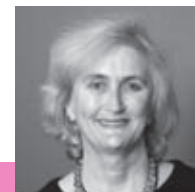
*Michael Happell*

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



*Karen Hayes (Deputy Chair)*

Karen has extensive business management, strategic consulting and human resources experience in Australasia, Canada, the United States and many European countries, primarily in the financial services and information technology industries. She is Director, Corporate Engagement & Human Capital with UXC Limited, having previously been the CEO of Planpower, a leading provider of project management and training services. She is also a member of the Board of the Melbourne Football Club. Karen was diagnosed with breast cancer in 1996.



*Andrea Hull, AO*

Andrea has been a CEO and senior executive in government and not-for-profit organisations for more than 30 years, most recently as CEO of the Victorian College of the Arts. She has a background in cultural policy and programs and arts education at international, national and state levels. She is currently the Deputy Chair of the National Museum of Australia, and a Board member of the Florey Neuroscience Institute, the National Gallery of Victoria, 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.



*Gabrielle Trainor*

A lawyer and former journalist and public sector executive, Gabrielle is a non-executive director and 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.

## Our patron



*Congratulations to you on 'My Journey Kit'. What a beautiful box of books and what an achievement it signifies. I am very proud to be the patron of such an inspiring network.*

*Quentin Bryce*

Her Excellency Ms Quentin Bryce AC  
GOVERNOR-GENERAL OF THE  
COMMONWEALTH OF AUSTRALIA

## The year in review

*During 2010 we worked tirelessly to fulfil our mission to inform, empower, represent and link together Australians personally affected by breast cancer.*

One of our priorities was to expand our support for women with breast cancer in rural and remote parts of Australia. These women often face extra challenges, including reduced access to treatment and services. To provide them with more information and support we linked them together through forums which we held around the country, and connected them through our newly launched Online Network. These have both proven to be particularly invaluable and effective ways to inform and link these women together.

Our programs, information resources and advocacy work focused on women's survivorship – improving the quality of life for women beyond their breast cancer. We communicated directly with our 50,000-strong membership about the issues they face as survivors and used their feedback to make informed, significant and meaningful changes to our future endeavours and the way in which we work.

A particular highlight of 2010 was the return of our spectacular *Field of Women LIVE* to the MCG. From the air, our Pink Lady symbol took shape as 14,000 people stood together, representing the number of Australians to be diagnosed with breast cancer in 2010, and bringing this statistic to life in a highly visual and meaningful way.

The *Field of Women LIVE* activated a whole community. It brought together the combined strength and energy of so many stakeholders – sporting, media, government and, most importantly, people whose lives have been affected by breast cancer – in a truly memorable experience. It also helped raise much-needed funds that enable us to grow our programs and to continue to provide free assistance and support to women across Australia.

At BCNA, quality and innovation is central to everything we do. Any fundraising we undertake must also raise awareness and be used to ultimately benefit our members. It is perhaps this genuine motivation that inspired some unexpected opportunities that came our way in 2010, including receiving a large sum as beneficiaries in the will of a grateful BCNA member from WA who passed away during the year.

Shane Crawford also approached us with the concept of walking from Adelaide to Melbourne to raise funds for BCNA. *That's What I'm Walkin' About* helped raise awareness of our profile and services, inspired the community, and raised hundreds of thousands of dollars.

At the end of 2010, with our three-year strategic plan in place, we have a strong base for future work. Our energy, as always, will continue to be focused on extending our programs and reaching those who will benefit most. We are in a strong position to really concentrate on those areas where we are likely to have the most influence and where the greatest gains can be made for women with breast cancer and their families.

Lyn Swinburne, AM  
Chief Executive Officer



## 2010 SNAPSHOT

### Our members

- Nearly 14,000 new members
- First Indigenous Community Liaison trained
- 45 new support groups

### Our services

- 82% of newly diagnosed women received a *My Journey Kit*
- Online Network launched with 2500 active members within six months
- 11 information forums held in regional Australia

### Our voice

- More than 3000 women involved in research projects
- Presented at four major national conferences
- 10 new Advocates appointed

### Our relationships

- 594 health professionals involved in the *My Care Kit* program
- Celebrated 10 years of partnership with Bakers Delight
- New partnerships established with BHP Billiton, Nissan Australia and Channel 9

### Our profile

- *Field of Women LIVE* 2010 united 14,000 people at the MCG
- Shane Crawford's *That's What I'm Walkin' About*
- 265 *Mini-Fields of Women* held across Australia and two internationally

## Our members

*Now that I've become Breast Cancer Network Australia's first Aboriginal Community Liaison I have found more people are coming and talking to me, talking about those sort of journeys that I had and what journey they'll have. — Aunty Marg*

When I was told I had breast cancer, all I could think about was the threat to my life, my future and my family.

I thought I could keep it to myself, deal with it and move on. But I couldn't. Instead I started to tell everyone – people who I worked with, men, anybody who wanted to know. I felt that they needed to know – not just about me but about what women go through and how serious it can be.

Hearing about other people's stories made me realise I'm not alone – that there are people out there who have been through what I have been through.

Now I have a much better understanding of why the work is being done and for whom it's being done.

*Genie,*  
Breast cancer survivor  
and BCNA Volunteer

One in nine Australian women will be diagnosed with breast cancer in her lifetime. Approximately 14,000 women were diagnosed with breast cancer in 2010. Thirty-eight women in Australia are diagnosed with breast cancer each day.

This diagnosis marks the beginning of a journey for each woman and the people around her. But the journey doesn't end with the end of treatment – there are approximately 140,000 women living in Australia who have had breast cancer.

BCNA is a grassroots organisation that supports not only newly diagnosed women, but all women and people who have been affected by breast cancer.

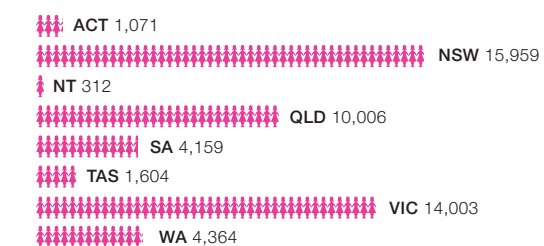
Our members are at the heart of everything that we do – they inform our services, our voice, our relationships, our profile and our organisation. Our members are women who are newly diagnosed, have secondary breast cancer or have been diagnosed in their lifetime.

At the end of 2010 BCNA had more than 50,000 individual members and 263 Member Groups throughout Australia.

Ninety per cent of our members have had a diagnosis of breast cancer. The remaining members have been affected by breast cancer through the personal experience of a family member or friend.

Behind all of these statistics is the face of a real woman with her own unique story. She is the reason BCNA is here.

BCNA members in each state (2010)



## The network

BCNA is a network of support groups and individual women who make a real difference in their local communities.

### Member Groups

Our Member Groups form the connection between our national network and communities all across Australia. They offer practical help and assistance to women diagnosed with breast cancer. These groups are mostly made up of women who have experienced breast cancer and who offer support and companionship to each other.

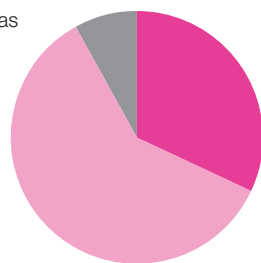
Member Groups receive our support with their activities and play a key role in passing information on from BCNA to group members and their local communities.

This year, 45 new Member Groups registered with BCNA, taking our total to 263.

The increasing number of Member Groups registered with BCNA ensures that more support is available to more women, especially those in rural and regional areas. It also helps us to develop and maintain a strong network of women in communities across the country.

Member groups across Australia (2010)

- Metropolitan areas
- Regional areas
- Remote areas



### Community Liaisons

Our Community Liaisons are individuals who have approached us wanting to know how they can give back to their communities and to connect with other women. Since 2007 we have run a program that helps these women speak about their own personal experience with breast cancer, raise awareness of the disease, and represent BCNA in their local communities.

Today, you'll find 220 BCNA Community Liaisons all around Australia. Hearing a woman who has been diagnosed with breast cancer speak about her journey is one of the most powerful ways to convey the impact of breast cancer and the importance of the work BCNA does.

Our Community Liaisons raise awareness of the impact of breast cancer, keep us connected to women across the country, and let us know what matters to women throughout their breast cancer journey.

As part of the program, women receive training and ongoing support to ensure they:

- are confident talking about their personal 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.

*I feel further inspired to support other women with breast cancer and there is always a need for greater awareness, education and support amongst the community. The training has certainly strengthened my capacity to do so.*

— Margaret



Everything changed from the moment I was told I had breast cancer. I was afraid and often angry. But, at the same time, I was determined and resolute that this was not going to be the end of me.

As such a young woman I think the experience was different to the average breast cancer patient – I have not had children, I was in a fairly new relationship, my friends found it difficult to cope. It was a very isolating experience. One where I was surrounded by so many people yet I felt completely alone.

BCNA saved me from a lot of anxiety and despair through thoughts of 'no one understands, no one cares now treatment is over, how will I know what information, drugs and resources are out there for me?' The *My Journey Kit* gave me a way of gaining, or at least the feeling that I was gaining, some control over what was happening. They gave me hope.

*Nikki,*  
Breast cancer survivor and BCNA Community Liaison

## Our services

*We want honest, upfront information so we can make informed decisions, but we want it presented with a sense of hope. BCNA's Hope & Hurdles Pack makes you realise there are women living, not dying, from secondary breast cancer. – Denise*

We understand that women with breast cancer have different needs, including how they like to receive information and support. We provide them with a range of free information, connect them through an innovative Online Network, and link them together in person at forums held throughout metropolitan, regional and rural Australia.

### Delivered directly to women

#### The Beacon

Our free quarterly magazine *The Beacon* has been a vital service for our members since 1998. Each edition includes stories from women sharing their experiences, as well as information on events, programs and issues relevant to women and their families.



*I want to tell you how encouraging and helpful your magazine is to me. Each copy seems to have at least one article that 'rings a bell' for me. It's good to know I am not alone and others have been through similar experiences as mine. Thank you. — Elizabeth*

*The Inside Story*, a supplement to *The Beacon*, began in 2006 and provides information and support specifically for women diagnosed with secondary breast cancer.

#### My Care Kit

Through our partnership with Berlei, BCNA offers a free *My Care Kit* to women who have recently had breast cancer surgery. The kit is our way of helping women adjust to the changes in their physical appearance, helping them emotionally as well.

It contains a Berlei bra especially designed to wear after breast cancer surgery and a soft form for women following a mastectomy. Kits are ordered for women by our network of breast care nurses.

In 2010, distribution of *My Care Kits* increased by 11 per cent with 9699 kits distributed.

BCNA's Online Network has definitely had a big hand in shaping me into the confident woman I am today. Being a young woman living in a small rural community with young children (2 and 4) I did not have access to support services that women in the city may have. I first learnt about the network at the 2009 BCNA Summit, and I have been a part of it since it went live.

The network was my lifeline at a very difficult time in my life. The women I met online were there for me 24 hours a day and I could ask anything. And I met my best friend online. We were the same age with children and going through chemo at the same time. We are now the best of friends and catch up in person whenever we can, despite living 4000 km apart. The Online Network gave me hope. If I had not had it then I would have felt so isolated and alone despite having a loving family by my side.

*Tanya,*  
Breast cancer survivor  
and BCNA member





**My Journey Kit**

The most valuable support and guidance for women affected by breast cancer is often from other women who have been there. The *My Journey Kit* is our free, comprehensive information resource produced by women for women who are newly diagnosed with breast cancer. It contains useful and practical information and tips, and directs women to many services and support networks that they may need on their journey.

The second edition of the *My Journey Kit* was published in 2010 and includes a new section on living with breast cancer which focuses on sexual wellbeing and relationships, and a CD specifically for partners.

A total of 11,355 kits were distributed in 2010, a 12 per cent increase on the previous year.

The *My Journey Kit* was received by 82 per cent of newly diagnosed women with 85 per cent of the kits distributed within one month of diagnosis. This ensured women received timely information so they were well-informed when making important decisions about their treatment.

*I have received the My Journey Kit in the post yesterday and a great new Berlei bra and prosthesis today! I am so thrilled with the level of support and service from your organisation. Obviously this is an extremely traumatic experience for someone of my age, however, the service that you provide really makes a difference. — Susie*

**Hope & Hurdles Pack**

For some women, their breast cancer returns in other parts of their body. BCNA offers women living with secondary breast cancer the *Hope & Hurdles Pack*. This free pack contains booklets, brochures, magazines and CDs that offer information, support and hope for women and their families.

In 2010, BCNA distributed 762 *Hope & Hurdles Packs*.

We also provide free ongoing and regular information to women to allow them to keep up to date and informed on key aspects of breast cancer research, treatment and care. This includes regular e-Bulletins reporting on the latest breast cancer research, and a range of fact sheets, including *Breast Cancer Pathology* (produced in partnership with The Royal College of Pathologists of Australasia) and *Depression and Breast Cancer* (produced in partnership with beyondblue: the national depression initiative).



**Online Network**



A diagnosis of breast cancer can be quite isolating, with many women telling us they felt incredibly alone when they were diagnosed. While information and education is important, connecting with people in a similar situation often provides the most comfort.

In 2010 we harnessed the power and reach of technology with the launch of our Online Network. This site is one of the first examples in Australia of social networking for a specific health issue and has met a significant need among our members.

Our Online Network has enhanced our ability to link people by giving those affected by breast cancer around Australia a way to connect no matter where they live, and at any time of the day or night.

*I have gained such fantastic support and a lot of answers to my questions. This is the site that has helped keep me sane through it all and I've talked to so many strong women who are so positive in their thinking. It definitely helps me to stay strong and positive as well.*

— Wendy

The Online Network is especially useful for women in rural and remote areas and for those who feel more comfortable sharing their thoughts and experiences in a secure online environment.

We trained 18 Online Network Champions who are regular and confident internet users and who check the site, warmly welcome new members and help existing members get the most out of the experience.

We also launched BCNA Member Group web pages, making it easier for women to find support groups in their area based on a simple postcode search. This initiative has also given support groups a template so they can upload and maintain their own information. They are able to promote who they are, what they do, upcoming events, and to share information, stories and photographs.

At the end of 2010, more than 2500 people had joined the site (39 per cent from regional Australia and 5 per cent from remote or very remote Australia). The majority of participants have been diagnosed with breast cancer (84%) and of those diagnosed with breast cancer, 25 per cent were under 44 and 75 per cent were over 44.

Overview of registered Online Network users according to breast cancer experience (DECEMBER 2010)

Location	Online network (n=2,439) <sup>1</sup>	Breast cancer incidence*
Major Cities of Australia	57%	68%
Inner Regional Australia	25%	21%
Outer Regional Australia	14%	9%
Remote Australia	3%	1%
Very Remote Australia	2%	0.4%

Age range	Online network (n=2,498)	Breast cancer incidence
Under 25	2%	0.07%
25-34	10%	1%
35-44	20%	11%
45-54	37%	23%
55-64	23%	27%
65-74	8%	18%
75+	1%	17%

\*% expressed is of average annual number of cases

<sup>1</sup> Breast Cancer in Australia, an overview 2009. Australian Institute of Health and Welfare and National Breast and Ovarian Cancer Centre. AIHW Cancer Series No. 50. pp 105, 115

Network activity has exceeded our expectations – in many instances participants have extended their friendships outside the network into Facebook, private messages, email and face-to-face coffee meetings.

We have received a lot of positive feedback from participants who appreciate the value of the Online Network and the experience of sharing their journey with others.

### Reaching rural women

Women in rural and remote Australia don't have easy access to the range of clinical services and support that women have in major cities. To reach these women we hold forums across regional and rural Australia, which deliver practical and insightful information to assist women to live well with and beyond breast cancer.

Our forums support women whose remote location and limited contact with specialist health care workers may impede their access to the full range of treatment options and support services.

In 2010 we held 11 forums across rural Australia, attended by more than 1400 people.

*What a wonderful, spirited and informative educational event we experienced in Bunbury. Your outrageously funny but caring and sincerely passionate team and well selected guest speakers hosted a truly diverse and informative selection of sessions. The feedback and networking I experienced throughout the day and beyond has been inspiring, encouraging and exciting for regional and rural women and their carers and families living with breast cancer. — Megan, Bunbury Forum*

These forums acknowledge the issues and challenges associated with living in rural and remote areas, focus on giving women strategies to increase their sense of health and wellbeing, and provide information on the services and assistance available in their local communities.

They also involve local/regional health professionals and community health services and offer rural women the chance to gather and meet with other breast cancer survivors.

We thank the following speakers who presented at the forums throughout the year: Stephanie Bennett; Pippa Blackburn; Assoc. Prof. Fran Boyle; Raelene Boyle; Dr Richard de Boer; Julie Campbell; Margaret Centra; Dr Jacquie Chirgwin; Margaret Collins; Stephanie Dowrick; Helen Goodall; Kathy Jones; Dr Carrie Lethborg; Kaye Matthews; Dr Nicole McCarthy; Assoc. Prof. Nicholas Wilcken; Donna Nichols; Dr Andrew Redfern; Lindsay Richmond; Dr Sid Selva-Nayagam; Dr Catherine Shannon; Karen Sprigg; Sandra Turley.

BCNA forums in 2010



(L-R) Raelene Boyle, Fran Boyle, Lyn Swinburne and Stephanie Dowrick



What a privilege it is for me to have taken part in the BCNA forums over the last 10 years or so and to see how powerfully they have developed. What seems to make so much difference is not just the priceless information that the forums offer but also the companionship and unstinting care that is at the heart of BCNA's work. I have seen over and over again what a difference this makes to each woman's personal experience. None of us can afford to be alone or to feel isolated when we have a serious illness – or when we are facing the life changes that follow it. It's one of the highlights of my working life to be part of this support network. And I must also mention what a delight it is to meet the women wherever we travel around Australia. It is always inspirational and uplifting.

*Stephanie Dowrick (far right), Breast cancer survivor and wellbeing presenter*



My advocacy work involves collaborating with others to make positive changes. It's an honour to work with people who are equally committed to finding better treatments and cures for those diagnosed with breast cancer.

My particular interest is high risk families – those with a BRCA 1 or 2 gene mutation and those in which the genetic mutation/s have not yet been found. My primary aim is to always ensure that consumers – those women diagnosed or women from high risk families – are represented.

As a BCNA Advocate I'm involved in the process at various levels. I've reviewed documents, publications, literature and questionnaires to ensure the language is understandable and user friendly. I've ensured the interests of women diagnosed or donating material for research are represented on research committees. I've presented at the Senate Community Affairs Committee hearing on gene patents. I've educated the media and medical students.

I've helped ensure the voices of women affected by breast cancer are heard loud and clear.

*Heather,*  
Breast cancer survivor  
and BCNA Advocate

## Our voice

*The longstanding and valued relationship with BCNA has been a major factor in ensuring that National Breast and Ovarian Cancer Centre's (NBOCC) work is informed by and responsive to the needs of consumers. BCNA brings a wealth of personal and collective stories to the table – the voices and experiences of women affected by breast cancer throughout the community. – Dr Helen Zorbas, CEO, NBOCC*

Our aim is to ensure the voices of women affected by breast cancer are heard wherever important decisions are made, and to improve access to breast cancer treatment and care.

We achieve this by working together with policy makers, health professionals, researchers, breast cancer and cancer organisations, and government.

### Advocacy

As more and more women are surviving breast cancer for longer, they face longer term issues. These survivorship issues are often different from the issues that women face while undergoing active treatment (i.e. surgery, chemotherapy and/or radiotherapy), and may include issues associated with fertility, breast reconstruction, physical wellbeing and long-term side effects, and emotional and sexual wellbeing.

In 2010, we collaborated with a range of groups to:

- secure and extend treatment options for women with secondary breast cancer
- assist young women to preserve their fertility
- ensure that women are aware of programs that financially assist them with the costs associated with breast cancer.

We also worked to make sure that the government and tax payers are getting value for money by ensuring the most efficient and cost-effective treatment options for women.

With the financial support of Cancer Australia, we conducted surveys with women in response to two key issues – whether women receiving the breast cancer treatment Herceptin were undergoing the required regular heart monitoring, and whether women are experiencing significant waiting times for breast reconstruction through the public health system. These are just a couple of examples of how we've used the experiences of women to inform our advocacy agenda.

During the year we also presented papers on a range of issues, including Herceptin and heart health and women's survivorship research priorities, at four major national conferences.

### Seat at the Table

As an organisation focused on women with breast cancer and those who support them, we believe it is imperative that their perspectives are represented in health research, policy and service delivery. Our *Seat at the Table* program is our way of ensuring their voices are heard. As part of this program, we attract, recruit, train, appoint and support women who have experienced breast cancer to participate in committees, boards and forums. These Advocates influence decision-making around breast cancer treatment, support and policy, and give a face and voice to breast cancer statistics.

Our Advocates are involved in 30 committees with the majority operating at a national level. They work with our 'sister' breast cancer organisations, government, health professionals and other national and international organisations to help improve outcomes for women across Australia. At the end of 2010 there were 71 BCNA Advocates, including 10 new Advocate appointments.

Since 2005, our women have also shared their experiences with the doctors of tomorrow in workshops at the University of Melbourne. These sessions are held

with students to help them understand the importance of the doctor–patient relationship and the need for effective communication throughout consultations.

## Consumer research

BCNA influences breast cancer research to ensure that it is meaningful and beneficial to women, their families and supporters, and to ensure the results are put into practice when appropriate.

We have the unique ability to directly reach women on our rich database of more than 50,000 members and to involve them in issues that are most relevant to them. This opens up incredible opportunities to inform research from a vital consumer perspective and not just from within the medical profession.

Throughout 2010, in response to feedback from our members about key issues, more than 3000 women participated in collaborative research projects which helped to inform our advocacy efforts and to improve the resources and support available to women. This included research on:

- developing a survivorship care plan
- studying physical activity and breast cancer survival
- designing an exercise bra specifically for women with breast cancer
- developing a comprehensive information resource for women on breast reconstruction
- identifying the information and support needs of women living with secondary breast cancer
- identifying and promoting women’s survivorship research priorities to researchers and health professionals through conference presentations and email alerts.

In order to identify the unmet needs of women affected by breast cancer, we commissioned an independent survey of BCNA members, as well as the broader audience of women affected by breast cancer and their support people. We found that women with breast cancer and their supporters want detailed information about treatments and side effects, confirming that we’re on the right track with our current resources and information. However, responses from the survey also identified significant gaps in the support available to those around the woman, and a key need for more emotional support services for both women and their supporters. The results of the survey will inform our program, policy and advocacy work over the next three years.

### Review & Survey Group

Our *Review & Survey Group* comprises approximately 800 women with breast cancer, who represent a cross-section of our membership. This group participates in various research projects and helps us stay in touch with what matters to our women.

*The BCNA Review & Survey Group was a fantastic resource for my research. I also had the benefit of a known denominator and an Australia-wide perspective. — Robyn Sierla, The University of Sydney*

We will continue to use the strength of our membership to identify the issues of importance to women and to influence key decision makers, to ultimately improve outcomes for women with breast cancer and their supporters.

When I was diagnosed with breast cancer in September 2008, I was impressed and grateful to receive the BCNA *My Journey Kit*, which helped me to understand what lay ahead. Having seen my mother and sister go through breast cancer treatment 15 and 20 years ago respectively, I came to realise just how much things had changed. It really brought home to me the importance of research and of the sharing of information, and that is why I decided to join the *Review & Survey Group*.

Since then, I have participated in several on-line surveys and book reviews. I was one of those who reviewed the revised *My Journey Kit*, to ensure that it gave newly diagnosed women the answers to their questions—and also hope and inspiration for a fulfilling life after treatment. In the past, women were told what they needed. Today we can tell doctors and researchers what we want and give them specific feedback.

*Chris,*  
**Breast cancer survivor**  
and BCNA *Review & Survey Group* member



## Our relationships

We know that working with others helps us get better results. We nurture close partnerships with many different organisations and individuals and, in doing so, strengthen our network and improve our support for women and their families affected by breast cancer.

Importantly, we reach women and gain a better understanding of their needs and the way the system works by working with the health professionals involved in their treatment and care, including doctors, nurses and supportive care professionals.

### Government

During 2010, the Australian Government supported BCNA in three of our key programs. As part of the *Supporting Women in Rural Areas Diagnosed with Breast Cancer Program*, the National Breast and Ovarian Cancer Centre (NBOCC) and BCNA received funding to undertake a joint program of work to improve supportive care for women in rural areas diagnosed with breast cancer. This helped us to host our regional and rural forums, conduct two rural and regional Community Liaison training programs, and develop our website and Online Network.



Australian Government

We also received significant contributions from the government towards producing and distributing the *My Journey Kit* and *Hope & Hurdles Pack*.

### Key partners and sponsors

We strive to build strong, long-term partnerships with key organisations that genuinely share our passion and commitment for our work.

Since 2000 we have nurtured a strong relationship with Bakers Delight. With more than 600 bakeries across Australia this unique partnership helps raise awareness of BCNA at a grass roots level and also unites the dedicated network of franchisees in supporting a good cause. This year we joined forces once again with bakeries and breast cancer survivors for the annual Pink Bun campaign. This event, which raised more than \$800,000 for BCNA, is a particularly effective way to promote our work, and to increase awareness of breast cancer and the people it affects.

We would also like to thank our partners and supporters during 2010 who helped us raise awareness, work cost-effectively, and reach more women through their own networks: Sussan, Australia Post, Pacific Brands, Berlei, Manildra Group, BHP Billiton, Nissan Australia, Channel 9, Bennelong Foundation, KitchenAid, Ernst & Young, Freehills, Multiwall, Precision Forme Cutting, Star Solutions, Naughtons Transport, PaperlinX and Vega Press.



Roger and Lesley Gillespie,  
Co-founders and CEOs of Bakers Delight

Major partner



Supporting partners



In the late 1990s BCNA campaigned, lobbied and demanded better access to information and specialised nurses. Patients under my care now have access to comprehensive, up-to-date resources, and the care coordination of specialist breast care nurses.

BCNA has always focused on addressing the needs of women with breast cancer and improving their access to services. It has facilitated access for breast forms and lingerie which has made an enormous difference psychologically, physically and practically for all my patients.

My patients and organisations such as BCNA have had a profound influence on my life both personally and professionally. The patients have made me a better person for having known them, and a better nurse for having cared for them. BCNA has empowered me to be a stronger and more vocal advocate for my patients within my workplace, and its resources perfectly complement the care I provide.

The comfort, support, inspiration and advocacy BCNA provides – not only for the men and women affected by the disease but also for the breast care nurses working at the ‘coal face’ – is truly astounding.

Jenny,  
Breast Care Nurse,  
Cabrini Health



## Our profile

*The Field of Women LIVE event is the best example of social marketing in cancer control and public health anywhere in the world. I was very pleased to support the event. The framed picture you kindly gave me has pride of place in my office. – The Hon. Daniel Andrews, MP (2010 Minister for Health, Victorian Government)*

Through national and local events, we activate communities across Australia, link people together, increase our profile and raise funds. Our events also help to ensure our members feel supported in their own communities.

### *Field of Women LIVE 2010*

On 7 May, 14,000 women and men (representing the number of Australians to be diagnosed with breast cancer in 2010) united on the Melbourne Cricket Ground to bring to life our Pink Lady silhouette. Survivors and supporters stood together in pink ponchos (100 in blue) in a moving and inspiring event that follows on from similar events held at Sydney's Telstra Dome in 2007 and the MCG in 2005.

*Field of Women LIVE* mobilises communities, businesses and government in a powerful display which raises awareness of breast cancer but, importantly, reinforces the message that women and families affected by breast cancer are not alone.

We thank the *Field of Women LIVE* major sponsors:

- Victorian Government
- Bakers Delight
- Sussan
- Australia Post
- Pacific Brands

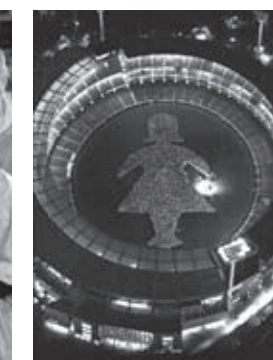
Event partners: Mantra, Ticketek, Spotless, RACV, City of Melbourne, AFL, MCG, Western Bulldogs, Herald Sun, Channel 7, New Idea, Melbourne Football Club.

It is hard to put into words the emotion I felt as I stood on the MCG for the 2010 *Field of Women LIVE*. Each face with a different story – many of survival, some of loss but all united through their own personal experience with breast cancer.

As I made my way around the field to talk to the participants and hear their stories, the messages of support and inspiration were overwhelming. When the lights went down and the Pink Lady sparkled we were united in a powerful image that was beamed around Australia and the world. Our community leaders and our BCNA members, their friends, family and colleagues all standing together as Kate Ceberano sang 'You will never walk alone' will long be remembered by all of us.

I am so proud of everything BCNA has achieved and I look forward to the future.

*Raelene Boyle,*  
Breast cancer survivor and  
BCNA Board member



Far left: (L-R)  
Marg O'Donnell,  
BCNA Chair;  
Deputy Prime  
Minister, The Hon.  
Julia Gillard, MP;  
The Hon. Nicola  
Roxon, MP;  
Lyn Swinburne,  
BCNA CEO.

## Community events

Local communities across Australia hold *Mini-Fields of Women* to pay tribute to and support those affected by breast cancer. Pink Lady silhouettes are planted in formation and tags with messages of support are placed on them.

Each community interprets the event to suit the local venue or setting, creating a wonderful variety of distinctive events. During 2010 BCNA provided free materials and support for 267 *Mini-Fields of Women*, including two international events.

Other events that raise awareness and funds for BCNA include *Pink Lady* events, *Pink Footy & Netball Day*, the *Sydney Morning Herald* Half Marathon, Run Melbourne and the Sussan Fun Run.

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

## That's What I'm Walkin' About

Following on from the *Field of Women LIVE*, Shane Crawford from Channel 9's *Footy Show* approached BCNA offering to run from Adelaide to Melbourne to raise awareness of breast cancer and BCNA.

The event united rural and regional communities who came together to cheer Shane on, wave welcome banners and donate for a special cause. Schoolchildren lined the streets holding homemade Pink Lady signs, communities rallied and people embraced Shane, sharing their stories and spurring him on to the finish line.

Twelve days, 780 kilometres and 70 towns later, Shane arrived at the Channel 9 studio in Melbourne to the cheers of supporters and a sea of pink.



From the moment I started out on the run from Adelaide I was blown away by the extraordinary reaction from the public. Through every country town, no matter how big or small, people came from everywhere to support me and those affected by breast cancer.

I feel privileged that so many people shared their stories with me on the journey. Each one affected me. I don't think a day went by without me shedding a few tears – a few times I did it with people that came out to see me, but mostly I did it on my own as I made my way along the road.

Sometimes the journey you start out on is very different to the one you find yourself looking back on at the end of the road. That's what happened to me in September 2010, and it was an experience that will sit with me for the rest of my life.

*Shane Crawford,*  
Television personality and  
BCNA supporter



## Our finances

With only 13% revenue from government, BCNA relies on community and corporate support to provide free services to people affected by breast cancer.

From a financial perspective 2010 was an outstanding fundraising year for us. A threefold increase in revenue from donations, events and merchandise contributed to a 51 per cent increase in total revenue compared to 2009.

We had two very successful fundraising events in the year: the *Field of Women LIVE* in May and Shane Crawford's *That's What I'm Walking About* Adelaide to Melbourne run in September raised \$822,000 and \$600,000 respectively. We were also the beneficiary of a very generous \$500,000 bequest from one of our members.

With such a strong year behind us, we have been able to initiate several new projects and are planning for significant growth in our programs and services over the coming years.

In 2010 membership, programs and services all grew significantly. Expenditure in these areas, however, increased by only 12 per cent as we were able to realise the benefits from improvements in operational efficiency. This result is particularly pleasing given the expense associated with building our new website and Online Network. It should be noted that we allocate operational overhead expenses such as rent back to the activity areas to provide a more accurate picture of the true cost involved in delivering services.

Revenue	2010 \$'000s	2009 \$'000s
● Donations	2027	612
● Fundraising	1598	1829
● Sponsorship	823	440
● Government funding	833	870
● Events & merchandise	780	253
● Investment income	156	107
<b>Total</b>	<b>6217</b>	<b>4111</b>

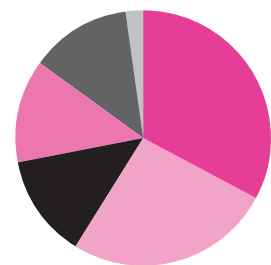
Expenses	2010 \$'000s	2009 \$'000s
● Programs & services	2845	2548
● Events & fundraising	1016	517
● Administration	249	184
● Impaired assets	231	0
● Depreciation & amortisation	16	2
<b>Total</b>	<b>4357</b>	<b>3251</b>

### Workplace giving

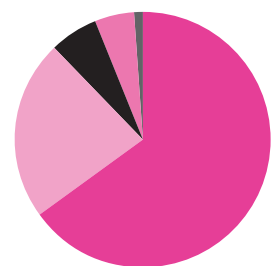
We thank the organisations which have invited BCNA to be part of their workplace giving program. In 2010 staff from the following organisations generously supported BCNA through these programs.

- Aviva
- BHP Billiton
- City of Boroondara
- Coles Group
- Collins Foods Group
- Macquarie Group
- NAB
- Sussan
- Target

BCNA revenue 2010



BCNA expenses 2010



## Our organisation

*BCNA is supported by a dedicated team of staff and volunteers who are passionate about helping women and their families affected by breast cancer across Australia.*

At the end of 2010, we had 24 FTE employees and enjoyed the generous support of 40 volunteers.

We are so grateful to our enthusiastic and committed group of volunteers who help us out on a daily basis. From collating and mailing out *My Care Kits* every week to promoting BCNA at events, we couldn't achieve everything we do without them.

Thank You



Breast  
Cancer  
Network  
Australia



293 Camberwell Rd  
Camberwell VIC 3124  
Freecall 1800 500 258

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