

# Diagnosed in Fiji, supported in Melbourne

VIRGINIA'S STORY

I think of my breast cancer diagnosis as my own personal roadside bomb. There I was, driving along my busy road of work and living, plans and worries, and – blam! – all turned over in an instant into a jumble of surgery, disability, pain, treatments, and frightened efforts to make sense of it all. Worse, my 'early' breast cancer, which was supposed to be so simple and have such a positive prognosis, was discovered the day after my breast surgery to have spread to my femur, so all at once I was an advanced breast cancer patient with possibly a frighteningly short future. And even worse, having been diagnosed in Fiji, which has no medical care for cancer like mine, I was forced to get treatment in the entirely unfamiliar city of Melbourne where I had no one at all – no friends, family, acquaintances, or even any history with Australia to draw on. It could have been a disaster on every level, not least emotionally.

So I'll never forget that day in Royal Melbourne Hospital when Jenny and Frederika from BreaCan materialised at my bedside. Shocked and bleary from two surgeries in three days and emotionally rocked by the incomprehensible news that I was dealing with advanced cancer, I think I saw small haloes over their heads. They explained who they were, and sat with me and heard my story with that extraordinary combination of complete focus, gentleness, care and respect that I later came to know as BreaCan's way. Even in that first hour, they created a small private bubble in the busy public hospital ward where I could talk, cry, shake and laugh in the confidence that I was with people who not only understood what I was going through but understood how to listen, support and advise, all at once. Frederika sat with me for a whole hour, and later called to check on me, giving me even that first day the sense that a safety net had somehow miraculously materialised for me and that I wasn't alone.

Later, when I was mobile, BreaCan's beautiful space in the Queen Victoria Women's Centre became like a second home. I could drop by when going to and from the hospital to share a cup of tea and my latest treatment news, share a bit of lore about cancer research, maybe participate in a workshop, and always be assured of

that kind, caring, focussed attention. Whether about matters small or large – and even 'small' matters are large, for those of us dealing with breast cancer – I always found solidarity, information, good conversation, and stories from other women with breast cancer

which helped put it all in perspective. Even on days when I didn't have time to swing by, or outside of the Centre's hours, when going about the City I felt more secure, easy and safe knowing BreaCan was there, feeling that I wasn't really by myself but

had a kind of family to turn to.

I've discovered, in talking to people about having breast cancer, that there is just no substitute for the experience of having it. However sympathetic, experienced and skilled other people may be, including professional counsellors, if they are not in the 'club' of those of us with breast cancer, they just don't quite get it. At BreaCan, everyone gets it. And, without fuss or pretence, the women at BreaCan share their experience partly by turning it into something life-affirming and positive, growthful and even, if you want to go there, a richer experience of life. Without them, it would have been far harder for me to find my way forward to what I can now say is a deeper sense of my own life, and my cancer journey would have been a lonelier and rougher road. There are no words for my gratitude for that gift – but then, with BreaCan, I don't need to explain, or even thank them, really, because it is something being shared, not given, and they already understand!



"(They) heard my story with that extraordinary combination of complete focus, gentleness, care and respect that I later came to know as BreaCan's way."

# Manager's Message

### ALISON AMOS BreaCan Manager





During this year of change, we have reflected on 'the fabric of BreaCan' – the things that make BreaCan special and unique. BreaCan has cemented its place as an innovative and effective model of information and support for women affected by breast and gynaecological cancers and their partners, families and friends. At the heart of this model is the service's approach to peer support, volunteering and active and meaningful engagement of women to continually inform and shape the service and its many offerings.

The emergence of 'supportive care' has been important in recognising the range of needs of those affected by cancer, well beyond a disease or medical focus. A focus on the five domains of supportive care needs (physical, social, psychological, spiritual and information) has underpinned a range of improvements to cancer services practice. In more recent years, the concept of 'cancer survivorship' has gained prominence as recognition grows of the far reaching impacts that cancer can have on the whole of a person's life and on the lives of those close to them. Distress has now also been formally recognised by the International Psycho-Oncology Society as a cancer vital sign that should be routinely measured.

These concepts of supportive care and survivorship align closely with the holistic women-centred model of service provision offered by BreaCan. BreaCan services are designed to support, inform and empower women as they adjust to being 'a woman with cancer' and navigate their way through the myriad of impacts on their lives, sometimes over many years.

The long term consequences of treatment can be profound – lymphoedema, treatment-induced menopause, infertility, sexuality, neuropathy and the list goes on. Many women also tell us that their cancer experience has changed them in a profound way as an individual and describe the process of adjustment and of finding 'a new normal' as a major life transition. Women can connect with BreaCan in a range of ways to access information and support to meet specific needs. This flexible approach is one of the key strengths of the service and is also reflected in the women's stories that are included in this *Year in Review*.

2011/2012 has been a time of change and transition for BreaCan. We have welcomed new members into the staff and volunteer teams and said our farewells to others. Of note is the departure of Helen Shepherd in March 2012 after nine years as the founding Volunteer Co-ordinator for BreaCan. Helen's substantial contribution to the development of BreaCan is acknowledged in a special thank you on page 16.

During this year of change, we have reflected on 'the fabric of BreaCan' – the things that make BreaCan special and unique. Many words and phrases were used to describe these elements: a focus on living well; deep understanding and connections between women; staff and volunteers act from the heart and with sincerity; commitment and passion; non-judgemental and inclusive; and a safe, nurturing environment. The foundation for these elements is the comprehensive peer support training that instils confidence in volunteers to take on this challenging role.

Many of these elements are also reflected in women's own words in the four stories that are featured in this *Year in Review*. These elements comprising the 'fabric of BreaCan' need to be nurtured, respected and carried forward as the service continues to grow and evolve.

It has been a great privilege for me to work with the talented and dedicated team of staff and volunteers at BreaCan this year. The team work tirelessly to provide a high quality service for Victorian women, their partners, family members and friends. Many of our achievements are highlighted in this publication and I have no doubt that the service will continue to grow and thrive in the year ahead.



**Alison Amos** 

## **Highlights**



Volunteer Nikki staffs a BreaCan trade display on a cold and wet day at Cruden Farm

#### **About Us**

BreaCan is a unique information and support service for people affected by breast and gynaecological cancers throughout Victoria. A service of Women's Health Victoria, BreaCan is committed to providing a women-focused service that is shaped by what women say. Since 2003, BreaCan has provided high quality supportive care in our city-based Resource Centre and in communities across Victoria through strong collaborative partnerships.

Growth in attendance at Group Sessions of 38%. page 5

Further evolved and strengthened our partnership with the Breast Service of the Royal Melbourne and Royal Women's Hospitals through the continued provision of the *Bridge of Support. page 7* 

Collaborated to improve care for women at the end of active treatment with the Breast Service, Western Health and the Inner North West Melbourne Medicare Local as part of the Victorian Cancer Survivorship Program. page 8

Increased our capacity to respond to the needs of women with gynaecological cancers through a successful project and ongoing partnership with Ovarian Cancer Australia. page 10





BreaCan's session (The Two of Us) was valuable because it provided an outlet for people to express concerns and gave us an opportunity to meet other couples as a couple and partners to meet other partners. Leanne

A group of women attending BreaCan's regional forum in Sale (pictured with Catherine Enter, McGrath Breast Care Nurse – far left)

Completed a two year project with Western Health seeking to improve access to information and support for women from culturally and linguistically diverse backgrounds. This has provided the basis for securing funding to further build our capacity in this area. page 7

Increased our volunteer workforce through the completion of training and orientation for the fifth intake of peer support volunteers and strengthened consumer participation through the formation of a BreaCan Volunteer Reference Group. page 17

Secured funding from the Department of Health to address some of our immediate space, infrastructure and information and communication technology needs. *page 11* 

Facilitated regional women's access to information and support through hosting forums in Sale and Geelong (attended by 93 women). page 14

Promoted BreaCan through speaking engagements, trade displays, forums and events. page 13

Extended our capacity through supporting student projects that progress BreaCan's strategic goals. These include IT system development (hosted by Monash University) and brand strategy development (hosted by RMIT University). page 12

Introduced a *What's New* newsletter enhancing our regular communications with women, service providers and friends of BreaCan. page 11

### At a Glance

- In 2011/2012 BreaCan recorded 2,821 contacts, the highest number of annual contacts recorded representing service growth in the past year of 15%.
- Service growth by contact type is shown in Table 1.
- An average of 17 people attended each of 82 group sessions (an increase of three people per session compared to 2010/2011). (see Table 2)
- 110 women received foot reflexology offered in 23 sessions across the year.
- Service users in 2011/2012 were from every region across Victoria with most growth in contacts from those living in north and west metropolitan Melbourne.
- Of the service users for whom cancer status was recorded:
  - 90% have experienced a form of breast cancer and 10% a gynaecological cancer
  - 21% reported their cancer as 'advanced'.
- 28% of service users were from a non-main English speaking country (compared with 17% in the Victorian population overall).
- The BreaCan website recorded a 50% increase in unique visitors to the website, including a 4% increase in the number of new visitors.
- 25 podcasts of information sessions were available to download via BreaCan's website (an increase from 13 in 2010/2011).
- BreaCan's mailing list grew by 14% to almost 3,500 individuals (2,654 service users and 842 service providers).

Table 1: BreaCan contacts

Contact type	Number of contacts	Growth since 2010/11
Individual contacts – Resource Centre	1,012	2%
Individual contacts – <i>Bridge of Support</i> at the Royal Melbourne Hospital	263	12%
Attendances at group sessions	1,422	38%

Table 2: BreaCan Group Session Overview

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Session type	2010/11	2011/12	2010/11	2011/12	
What's On Info Sessions	35	36	489	768	
Feed Good Gentle Exercise	23	23	274	376	
Information forums, regional visits, workshops	5	8	145	165	
Making Connections Info Sessions for women living with advanced cancer	5	7	69	81	
Here and Now Group program	7	8	53	32	
Total	75	82	1,030	1,422	

<sup>\*</sup> An individual may have attended more than one session



A meeting of the BreaCan Volunteer Reference Group

## Bridge of Support Noula's Story

Early last year I found a lump in my right breast and was then diagnosed with breast cancer in April 2011. My initial diagnosis was early detection – Grade I, an operation for a lumpectomy, chemo not likely, possible radiotherapy and a hormone drug for five years.

Thankfully my Breast Care Nurse had provided me with BreaCan's pamphlet and a week later I dropped into BreaCan for the first time. The women I met on that day were wonderful, they knew how to get me to share where I was up to in my cancer journey, they provided me with information, book lists, reflexology and most of all support from volunteers who knew first-hand what I was going through.

A few weeks later the diagnosis changed to needing both chemotherapy and a mastectomy. In that moment I realised that I no longer had 'a little bit of cancer' this was now personal. This cancer was taking away my right breast, my beautiful blonde long hair, my ability to work and make a living – my independence. I also faced the possibility of many horrible long and short term side effects due to all the treatments.

Still frightened at the thought of chemotherapy, I had heard that BreaCan offered the *Bridge Of Support* service where staff and volunteers came to the hospital once a week at the Royal Melbourne Hospital. I made sure my chemotherapy treatment days would coincide with this service so I could attend.

This is where I met Helen who worked for BreaCan and she made me a cuppa and asked me to sit down in a nice room away from the chemo waiting room, with other women sipping on lovely green tea on comfy couches. Helen also advised me of other services provided by BreaCan (such as the exercise group and other vital bits of information) ... it was like she was psychic and knew what was around the next corner and prepared me for it. Coming away from a catch up with Helen always felt like good medicine. I then listened to the volunteers who shared their stories with my sisters and I. These two women, both survivors, had amazingly inspirational stories to share.

I felt connected to peer support volunteer Mary instantly. I could see that she had walked in the same shoes as me and she looked so healthy and vibrant with lovely long hair.

They both gave me such hope ... they turned my fear into comfort and through their stories I could see light at the end of the tunnel. They also supported my sisters after I was called in for my treatment. Helen came by and said goodbye before she left. Although I value the entire service and support I've received from BreaCan, I cannot express how important the *Bridge of Support* service was for me.

So now my treatment is complete and my doctors are very happy with my prognosis. I am on a waiting list for a breast reconstruction although I'm in no hurry, happy to keep healing and getting stronger before I embark on more surgery. I still utilise BreaCan's services such as dropping in for a chat if I need to, borrowing books and attending many workshops and seminars.

I hold on to hope and feel grateful for the amazing people that have presented themselves throughout my journey thus far: my medical team; my Breast Care Nurse; and BreaCan staff and volunteers for countless conversations. I am also grateful to my beloved family who supported me emotionally, physically and financially throughout this ordeal and to my extended family and friends for all their love and support. Most importantly, I am thankful for every single day that I get to share this beautiful thing we call life.



"I then listened to the volunteers who shared their stories with my sisters and I. These two women, both survivors, had amazingly inspirational stories to share."

# **Increasing Our Access**

STRATEGIC GOAL 1

Increasing access to BreaCan services through the implementation of new and innovative programs, collaborations, partnerships and events, continues to be a major strategic focus of the service. In 2011/2012 BreaCan partnered with a number of cancer organisations, health services and community groups to increase information and support provision to specific underserved and often hard to reach groups.

We highlight three examples from our work in 2011/2012 focused on increasing service use or creating new pathways to access for women.

#### The Bridge of Support – here to stay

Over the years, many women have told us that they wished they had been able to access BreaCan services around the time of diagnosis and whilst undergoing active treatment. The *Bridge of Support* evolved as a potential way of taking the BreaCan peer support model to women and providing a bridge to a community-based service that could endure well after regular connection with the Breast Service had ceased.

Since April 2010, BreaCan has provided a weekly peer support service at the Breast Service of the Royal Melbourne and Royal Women's Hospitals. When the initial pilot period ended in September 2011, the success and value of the service was well recognised and it has continued to operate since that time. The service has also changed its hours and days of operation to better align with the timing of key clinics to improve accessibility for women.

The evaluation of the pilot has demonstrated a strong uptake of the service and a significant value placed on the service by the women, their families and friends and by the personnel of the Breast Service. In 2011/2012, 263 peer support contacts were made through the *Bridge of Support* with women with breast cancer, family members, partners and friends. A service reach of 64% was achieved (127 women with breast cancer of the approximately 200 new breast cancer patients seen each year by the Breast Service). This represents a 39% increase in service reach since 2010/2011. BreaCan and the Breast Service remain strongly committed to this highly successful partnership and to sustaining this important service in the long term.



The *Bridge of Support* has been an excellent initiative, bringing the supportive approach of BreaCan to where the patients most need it.

Prof Bruce Mann



Women enjoy the relaxing art of Japanese embroidery, Sashiko

#### Bridging the cultural divide for women in the west

In December 2011 BreaCan completed a two year project that was undertaken in partnership with Western Health seeking to identify and address the information and support needs of women from culturally and linguistically diverse backgrounds. The project, funded by Cancer Australia, was a great success and has provided an important foundation upon which BreaCan will further build.

Key outcomes from this project have included:

- An improved understanding of the information and support needs of women through the conduct of focus groups and many individual conversations with women affected by breast or gynaecological cancers
- The successful delivery of a series of programs for women with a focus on connections with women from diverse cultural backgrounds including two community forums (one general and one for Vietnamese women) and a five week 'Steps for Fun and Fitness' exercise program in Yarraville

### Increasing Our Access STRATEGIC GOAL 1

- Engagement with women and interpreters with an active interest in working with BreaCan to continue to improve accessibility of our services on an ongoing basis
- Incorporation of cultural competency-based sessions into BreaCan peer support volunteer in-service programs
- A series of recommendations that have guided the development of a plan to continue to build BreaCan's capacity to respond to the diverse needs of women.

This project provided a strong foundation on which to base a successful application for funding from Cancer Australia in their next grant round. BreaCan will commence a new two year project in July 2012 to develop and implement a diversity strategy and continue to grow and shape a best practice model of information and support for Vietnamese women, the lessons from which will be transferrable to other cultural groups.









#### From supportive care to survivorship

BreaCan is proud to be a partner in a two year project funded by the Department of Health as part of the Victorian Cancer Survivorship Program. This project, a collaboration with the Breast Service of the Royal Melbourne and Royal Women's Hospitals, Western Health, the Inner North West Melbourne Medicare Local and BreaCan commenced in December 2011. The project aims to improve the transition to survivorship after the end of treatment.

BreaCan's role in the project is to:

- Facilitate consumer participation in the project
- Develop and coordinate the evaluation of the project
- Trial an electronic mechanism for the routine referral of women to BreaCan around the time of diagnosis
- Develop a suite of 'navigation tools' on a series of topics that direct women towards key reading material, websites or services they may find useful to explore.

Through this partnership, BreaCan hopes to contribute to: identifying ideal models of care to support women at the end of active treatment; women being well supported, informed and empowered to identify and work through their unmet needs at this time; women being aware of and connecting with community-based support services that can assist in their pathway to wellness after cancer treatment.



Meeting other women who are 'walking the walk' – while professionals say they understand how we feel and although they display empathy, this is on a different level.

Jane, living with advanced cancer

## Just the right time MARY'S STORY

This is my story. I was diagnosed with ovarian cancer in February 2009. Prior to that in 2008, two close family members - my father and sister-in-law - tragically passed away. They say things come in threes. but I didn't really believe that ... after all it just couldn't happen. I wasn't going to die as well ... how much more could this family take?

The news after the biopsies was good and bad ... not advanced but very aggressive serous cancer so I still needed chemotherapy. In February I had surgery to remove my left ovary. I was told I would need surgery again in six weeks for a full hysterectomy as the large mass was definitely cancer. I was rather annoyed because just as I was healing from the operation I had to do it all over again! I was treated with chemotherapy, beginning in April and finishing in August the same year.

The day my GP told me she was sorry as they suspected cancer. I was at home on my own. The first thing I found myself doing was try and "process" what I had just heard. I wrote down all the important things in my life, and then I sat in the garden and couldn't help noticing the native frangipani tree. It was in its full majestic bloom. There was a slight summer breeze and as it gently swayed from side to side, it shared its exquisite perfume. A strange overwhelming feeling came over me and ultimately I knew there was too much to miss out on. Life was to be cherished and even the simplest things can make you want to live and appreciate every moment. At that intense moment I was not afraid of dying ... I was afraid of not living.

Here I am three years later and writing my story for an organisation who crossed my path at "just the right time". I had heard about BreaCan whilst having chemotherapy at the wonderful Mercy Hospital from the ever so lovely and caring social worker Rosemary. At that time I was in survival mode so any extra thing to do was just way too much. However, I do remember thinking I could be interested sometime in the future.

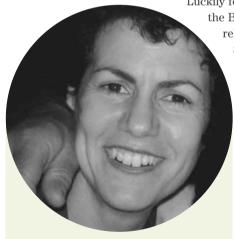
> Luckily for me, logos do work. I was in the city one chilly winter day and happened to see the BreaCan sign. This triggered an emotion, I was still having regular check-ups with relatively good news each time. So why was I still feeling like something was wrong.

Shouldn't I be feeling better by now? Well at least that's how I perceived it. I had lost all my sense of self, was experiencing low self esteem and the confidence I once had seemed to have vanished. Although I was feeling okay physically, I wasn't

okay emotionally. I needed more than just counselling and loved ones' support. What I needed were other women who were experiencing similar issues. I needed someone who would listen and just see it as it was.

When I arrived home that day I went online and found BreaCan. It took me another two weeks before I registered to attend one of their information sessions ... and then an email invited me to chat with a peer support volunteer. Kirsten was just marvellous and I will never forget her warmth and encouragement. So now the seed had been planted and looking back now it was the best thing I could have done for myself.

Another year has since passed and I have accessed many services from BreaCan. Reflexology ... just divine! I have attended a few seminars and workshops where I have met and shared some similar experiences with other women. The feeling of knowing they understand what you mean is invaluable. At BreaCan there is always a welcoming smile by both staff and volunteers who are professional and passionate. By being part of BreaCan I know I have the support when I need it. It's always difficult to know when a woman with a gynaecological cancer may need support – providing that the service is there, they will know when the time is right.



"Although I was feeling okay physically, I wasn't okay emotionally. I needed more than just counselling and loved ones' support. What I needed were other women who were experiencing similar issues."

### **Expanding Our Capacity** STRATEGIC GOAL 2

BreaCan has grown and evolved considerably since the doors of the service first opened to the public in April 2003. The reach of the service has been extended through the development of new programs such as the Bridge of Support. BreaCan forums in different communities across Victoria and project work. Expanding our capacity requires a balanced approach to ensuring

adequate resources to meet

service demand without ever

compromising the quality of

service provision.

In 2011/2012 BreaCan expanded its capacity through increasing the volunteer workforce, securing funding to support specific project and capacity building initiatives, developing new productive partnerships and supporting student projects that directly relate to our strategic objectives. Our work with Ovarian Cancer Australia and some of our specific capacity building initiatives are highlighted here.



BreaCan and Ovarian Cancer Australia hosted an information session and afternoon tea as part of the Cancer Australia funded project

#### A productive partnership with Ovarian **Cancer Australia**

Supported by a grant from the Department of Health, BreaCan has worked in partnership with Ovarian Cancer Australia to provide women with gynaecological cancers with improved access to information and support that is responsive to their needs. We have also sought to increase engagement with the gynaecological cancer sector. The highlights of this project in 2011/2012 include:

- Forty seven women chose to engage with the project with individual interviews undertaken with 23 women with a gynaecological cancer and ten service providers who care for women with gynaecological cancers to identify information and support needs and barriers to access and referral
- Attendance of over 50 women at a celebration of Ovarian Cancer Awareness month and information session about the latest advances in ovarian cancer research
- Nine women attended a 'Caring for You' session specifically for women with gynaecological cancers as part of the BreaCan What's On program of events
- Regular communications with women about programs and events offered by BreaCan and Ovarian Cancer Australia that may be of interest, as well as opportunities for women to become involved in research and/or to act as consumer advocates
- An increase in the proportion of BreaCan contacts that were women with gynaecological cancers from 8% in 2010/2011 to 10% in 2011/2012.



The presentation was good but I really enjoyed connecting with the women around me - chatting about 'our story'. Sophia

> This project has been a very positive demonstration of how two community-based organisations with shared goals can work together to increase information and support options available to women and their supporters, expanding the capacity of both services in the process.

> BreaCan will continue to actively engage with these women, the gynaecological cancer sector and in our productive partnership with Ovarian Cancer Australia to the completion of this project in September 2012 and beyond.

### Expanding Our Capacity STRATEGIC GOAL 2

#### Capacity building from all angles

Expanding our space and infrastructure

BreaCan has successfully secured a one-off grant from the Cancer Strategy and Development Unit of the Victorian Department of Health that will provide some much needed capacity to increase our office space and infrastructure. This small increase in space will accommodate our growing team and provide a new multipurpose space that will support the provision of individual therapies such as: reflexology; small group sessions; meetings; and also provide a volunteer workspace separate from the Resource Centre. The grant will also improve our information and communications technology capability through enabling teleconferencing and videoconferencing to improve access for people who are not able to travel to the Resource Centre.



A meeting of the Volunteer Reference Group



The day generated a warm connectedness and safe nurturing environment for the group of women who all have an experience of breast or a gynaecological cancer, in a rural environment.

Catherine (Breast Care Nurse commenting on Rural Forum)

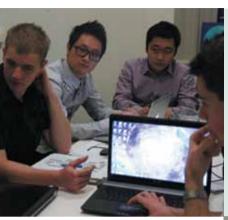


A copy of the What's New bulletin that can now be received in html email format

Enhancing communications with What's New

In October 2011, the first edition of *What's New* was included in our quarterly mailout of BreaCan programs of events. *What's New* has been incorporated into our routine communications with our mailing list members since that time and provides a valuable mechanism for communicating about new resources available through the BreaCan library, links to other information and support options that people may choose to access, BreaCan updates, forums and research projects.

### Expanding Our Capacity STRATEGIC GOAL 2



Monash University IT students meet with BreaCan staff to discuss progress on client and volunteer management systems development

#### $Supporting\ student\ projects\ that\ progress\ BreaCan\ strategic\ goals$

In 2012, BreaCan was selected as an industry partner for a Monash University IT Industry Experience Project. The project, which continues to the end of the 2012 academic year, involves two teams of four students each working on the development of a tailored BreaCan client and volunteer management system. If successful, this system will substantially improve the quality and accessibility of data, streamline current processes and enhance our capability to monitor, evaluate, improve and report on our service performance.

In 2012, RMIT Masters in Marketing students worked in 19 teams to review WHV and BreaCan branding and to develop and recommend a brand strategy. This was a positive partnership where BreaCan was exposed to multiple critiques of our



brand and promotions from primarily a younger person's perspective. The students have provided us with some great ideas and suggested techniques that we will take forward when planning our communication strategy.



The students have provided us with some great ideas and suggested techniques that we will take forward when planning our communication strategy.

#### Reorganising the BreaCan team to enhance our capacity

In 2011/2012, a reorganisation of the BreaCan staff team was implemented. This was designed to optimise the resources available within our staff team as well as provide a clear structure, roles and responsibilities. One element of the new structure is the allocation of a series of portfolios across the team to promote the development of specific expertise. These include core areas such as advanced cancer and gynaecological cancers as well as a set of six diversity portfolios including: women from culturally and linguistically diverse populations; Aboriginal women; women with disabilities; women from rural and regional Victoria; women from the GLBTI community and women experiencing socioeconomic disadvantage.

## **Extending Our Influence**

STRATEGIC GOAL 3

BreaCan has an important contribution to make to the supportive care and emerging cancer survivorship agendas. Our contribution is made through the services we provide, through productive collaborations, effective partnerships and the sharing of knowledge and expertise gained from nine years of service provision to Victorian women.

Achievements in 2011/2012 in extending our influence include:

Participation in a range of cancer sector activities including the Breast Cancer Network Australia National Summit, COSA Cancer Care Coordinators Conference, SolarisCare Symposium on complementary therapies and cancer; participation in the review of the Victorian Integrated Cancer Services.

**Presentations and meetings with international colleagues** including: delegates from the Department of Health of Cambodia; and the founders of OvaCare – a new charity seeking to adopt a similar model to BreaCan for women with ovarian cancer in Ireland.

Membership of and participation in: the Victorian Cooperative Oncology Group Breast, Gynaecological and Psycho-Oncology committees; the Victorian Cancer Survivorship Program statewide steering committee; and the Victorian Cancer Survivorship Program Community of Practice.



Great to see an effort being made to collaborate with a range of groups, support services and providers.

Ann, attendee at a collaborative forum

**Promotion of BreaCan events** through articles in *The Senior* newspaper, *The Beacon* and regional papers for specific activities.

Promotion of BreaCan through speaking engagements, volunteer involvement and/or trade displays at the following events: Chinese Cancer Society of Victoria Information Day; Cabrini Hospital Pink Ribbon Day; Ramsay Health and BCNA event at Cruden Farm; Epworth Hospital Awareness Expo; Maroondah Breast Clinic Breast Cancer Awareness

Day; Austin Hospital's Breast Cancer Information Forum; Monash End of Treatment Group; Melton Country Club's celebration of Cancer Council Victoria's biggest morning tea; Breast Care Nurse in-Service; BreastScreen radiographer meeting; BCNA Warrnambool forum.

**Contribution of staff and volunteers to service planning consultations** for the Olivia Newton-John Cancer and Wellness Centre at Austin Health and the Victorian Comprehensive Cancer Centre.

Provision of input into research design and/or promotion of research studies relating to experiences of women with breast and ovarian cancer undertaken by the University of Queensland and Deakin University.



#### Special acknowledgment to Lyn Swinburne

Lyn Swinburne, Founder and CEO of Breast Cancer Network Australia retired in November 2011. Her farewell was celebrated at the National Gallery of Victoria with a wonderful tribute to this passionate advocate for women with breast cancer. Through her role as a consumer advocate and Chair of the Breast Care Implementation Advisory Committee Lyn played a key role in the creation of BreaCan.

L-R Dina Lynch, Sally Fawkes, Rita Butera, Lyn Allison, Frederika, Helen Shepherd, Rhonda, Alison Amos and Wendy Pullan, attending the official farewell party of Lyn Swinburne, founder and CEO of BCNA

### Not all roads lead to Melbourne

ALANNA'S STORY

After giving up work in 2011 to complete the final year of my Primary Teaching Degree, I was looking forward to starting my new career in February 2012. It had been a tough year and I had been devastated to lose my beautiful Mum to lung cancer at the end of October (during my final exams and assessments). This had been the most stressful time in my life.

One of the last days out I had with my Mum was when she accompanied me to a biopsy on a 0.5 cm breast cyst I had had for a couple of years. The doctor assured me it was just a cyst again but thankfully he also told me to have a routine mammogram. I was surprised to be told that there was extensive calcification in my left breast (unrelated to the cyst). After a tissue biopsy I was told to visit a breast surgeon in Melbourne in two days time.

'You have breast cancer in your left breast and I recommend a mastectomy,' the doctor told me. This began a terrifying whirlwind couple of weeks where I had to make six trips to Melbourne for a multitude of tests and consultations with the surgeon and plastic surgeon. Quite a difficult and exhausting feat when you live three and a half hours from Melbourne and have three children who have just started their first days back at school.

In early March I had a tissue-sparing mastectomy. I only needed one night in hospital but needed to find accommodation near the hospital for seven days in case of complications. My husband and I were away for nine nights and my Dad did a fabulous job of looking after the kids. I was amazed at how well I recovered after the operation and was very relieved that there were no lymph glands involved which meant no chemotherapy and no radiotherapy. I still had weekly visits to Melbourne to see the plastic surgeon for my two stage reconstruction.

I was given a BreaCan brochure by my Breast Care Nurse which outlined many of the services which were available in Melbourne and thought to myself, 'it would be so much easier if I lived in Melbourne and I could take advantage of these services'. With all the trips to Melbourne I was already doing for medical appointments, it was

impractical to think about going down more often to visit the fantastic services that BreaCan provide. Fortunately for me, BreaCan had plans to overcome this obstacle.

Shortly after my operation I was given an invitation to attend a Breast Cancer Information Forum for women living in Gippsland which was only 50 minutes from

where I live. 'Wonderful!' I thought. 'Now I can access some of those fabulous services that I had read about.' I nervously went along, not knowing anyone else who was attending. What a fabulous day it was! A few months had passed since my operation and I had begun feeling quite low but I believe that this BreaCan Information Day provided a turning point for me. The first session was about living well after a cancer diagnosis, where a psychologist spoke about how cancer has impacted on women's minds, their bodies and their relationships. She provided some practical tools to assist with living well following a cancer experience which I found very helpful in overcoming my low moods. This was followed by a seminar about breast reconstruction by a plastic surgeon which was very informative and relevant to my situation. The afternoon session involved choosing an activity from Tai Chi, Meditation, Music Therapy or Art Therapy. The session that I believe was most beneficial to me was the Art Therapy Session. The session was carried out in such a caring and nurturing way - I found it an emotional experience but very therapeutic. One of the most special parts of the day was meeting other women who had all had similar experiences and realising I was not alone in this journey. I have kept in touch with several women that I met on that day and have found their support and friendship very helpful in my recovery. Thank you BreaCan for providing this wonderful opportunity to the women of Gippsland.

SI

"A few months had passed since my operation and I had begun feeling quite low but I believe that this BreaCan Information Day provided a turning point for me."

## **Our Information and Support Services**

For most people affected by cancer, providing clear information that is tailored to needs and preferences and an opportunity to talk through their experience and concerns is a valuable way of alleviating anxiety and distress. BreaCan's core business is to inform, support and empower women with breast and gynaecological cancers and the people who support them.

#### At the BreaCan Resource Centre

- One-on-one contact with peer support volunteers in person at the Resource Centre
  or by phone or email.
- An extensive information library including books, journals, CDs and DVDs for people
  to browse or borrow and a display of breast forms, bras, wigs and accessories. A number
  of information sessions are also recorded. The CDs can be loaned through the Resource
  Centre library and podcasts are available to download via the BreaCan website
  (www.breacan.org.au/services-events/information-sessions/archive).
- Free **reflexology** appointments provided by a trained nurse and reflexologist for women at the Resource Centre, an important form of relaxation and a prompt for many women to seek out other forms of relaxation or self care.
- Referral to other support services as required.

In 2011/2012 BreaCan hosted 36 What's On and seven Making Connections information sessions. These included talks by health professionals about various clinical issues, workshops focussed on creative therapies and wellness and opportunities for social connections with other women. A number of new topics were offered in 2011/12 in response to feedback from women. These sessions are shown in bold italics in the list below:

- Information sessions: Advanced breast cancer and bones; A naturopath's approach; Anxiety; Bras, boobs and breast forms;
   Breast cancer and bone health; Cancer and the emotional roller coaster; Caring for our personal energy; Demystifying Chinese Medicine; Enhance your wellbeing; Fatigue To rest or not to rest?; Gynaecological cancer research update: The Australian Ovarian Cancer Study; Lymphoedema; Making a choice: what you need to know about breast reconstruction; Managing menopause after cancer; Music for the mind, body and soul; Older, fitter, stronger; Shrinking the worries; The two of us: a session for women and their partners; Sleeping soundly; Treatment for advanced cancer: options and opportunities;
   What it means to have a family history of cancer; Your immune system and cancer
- Creative therapies and wellness workshops: African drumming; Art therapy; Caring for you for women living with aynaecological cancer; ChiBall; Creative Writing Workshop; Japanese Hana Flowers; Meditation; Tai Chi; Wordplay; Yoga
- Social gatherings and connections: Afternoon Teal (with Ovarian Cancer Australia celebrating Ovarian Cancer Awareness month); Book launch – Journey: Experiences with breast cancer; Coffee, cupcakes and connections for women with advanced cancer; The generosity of giving (fundraiser for WHOW – women helping other women)

A number of information sessions were also recorded and can be loaned from the Resource Centre. Podcasts of 25 information sessions can also be downloaded from www.breacan.org.au – just click on the link to podcasts on the homepage.

#### In the Community

BreaCan also outreaches to women in their local communities through free information forums, gentle exercise programs and through the *Bridge of Support* program. In 2011/2012 these activities included:

- The Feel Good Gentle Exercise Program offered on a fortnightly basis in the city and conducted by a trained fitness instructor who has personally experienced breast cancer. The program offers gentle exercise to tone the body and improve lymphatic flow.
- Steps for Fun and Fitness is a five week exercise program, it includes a variety of gentle exercises to improve fitness and regain confidence following cancer treatment. One program was offered in Yarraville as part of the Western Health project.
- All day Information Forums in metro, regional and rural locations. Forums comprise presentations by guest speakers on relevant cancer related topics and creative therapy and wellness workshops. In 2011/2012 BreaCan hosted forums in Geelong, Sale and Altona with 98 women attending.
- The *Bridge of Support* at the Breast Service of the Royal Melbourne and Royal Women's Hospitals operates alternate Tuesdays and Thursdays.

## **Our People**



L-R Fiona McRae, Robin Curwen-Walker, Kellie Holland (seated), Wendy Pullan, Alison Amos (seated), Katherine Bradstreet, Jenny Rigby, Justine Dalla Riva

#### Staff

Alison Amos MANAGER

Katherine Bradstreet

Robin Curwen-Walker PROGRAMS OFFICER

Justine Dalla Riva COMMUNICATIONS AND INFORMATION MANAGEMENT CO-ORDINATOR

Kellie Holland VOLUNTEER AND CONSUMER PARTICIPATION CO-ORDINATOR

Fiona McRae
TEAM LEADER, PROGRAMS

Wendy Pullan PROGRAMS OFFICER

Jenny Rigby
PROGRAMS OFFICER

#### **Farewell to Staff**

Nicole Wilton INFORMATION AND SUPPORT OFFICER (FINISHED SEPTEMBER 2011)

Rebecca Tipper PROJECT OFFICER (FINISHED DECEMBER 2011)

Helen Shepherd SERVICES AND VOLUNTEER CO-ORDINATOR (FINISHED MARCH 2012)

#### Special thanks to Helen Shepherd

Services and Volunteer Co-ordinator Helen Shepherd (pictured opposite) was farewelled by staff and volunteers at a celebration on March 2, 2012. Representatives from each of the volunteer intakes spoke movingly about Helen's work and the support she has provided to them in being able to share their experiences with confidence. Helen has made an extraordinary contribution to the development of the Volunteer Program at BreaCan. Her founding work, along with that of Di Missen (former BreaCan Manager) has placed the organisation in a strong position to expand into the future.

#### The BreaCan Advisory Group

The BreaCan Advisory Group membership is:

- Sally Fawkes Chair (WHV Council Member)
- Lyn Allison (Political Advisor, WHV Council Member until October 2011)
- Heather Beanland (Consumer)
- Helen Coleman (WHV Council Member)
- Christine Evely (Consumer)
- Bronwyn Flanagan (Breast Care Nurse, The Royal Melbourne Hospital)
- Jane Fletcher (Consumer)
- Claudia Ginn (Consumer)
- Jane McNeilage (Gynaecological Oncologist, Monash Medical Centre)
- Annabel Pollard (WHV Council Member)
- Penny Sanderson (Manager, Mercy Lymphoedema Clinic)
- Katy Weare (Cancer Services & Complex Care Manager, The Women's Hospital)
- Rita Butera (WHV Executive Director)
- Alison Amos (BreaCan Manager)

Thank you to Annabel Pollard who finished as Chair of the Advisory Group in November 2011.

#### Message from the Advisory Group Chair, Sally Fawkes

It is vital that our community ensures that each and every woman in Victoria who develops breast or a gynaecological cancer can access the types of information and support they need, when and where they need it, with no financial or language barriers. In line with this vision, and due to the commitment of its volunteer and staff team, BreaCan has been an innovator of information and support services for women diagnosed with these cancers since it started in 2003. The drop-in and telephone peer-support programs, group activities and Bridge of Support program have become mainstays of BreaCan's work. As a WHV Council member, I have watched BreaCan grow and was this year honoured to take up the role of Chair of the BreaCan Advisory Group.

I wish to thank Dr Annabel Pollard for her wise and knowledgeable chairing of the Advisory Group over the past five years. I look forward to working with the highly skilled and experienced members of the Advisory Group and the BreaCan team in the upcoming year. Together, we must ensure the valuable work of BreaCan continues to provide for the diverse emotional, social and practical needs of Victorian women living with breast or gynaecological cancers. There is also much we can do to expand our reach, relevance and responsiveness by initiating and engaging more actively in listening projects, research and policy dialogues.

"Together, we must ensure the valuable work of BreaCan continues to provide for the diverse emotional, social and practical needs of Victorian women living with breast or gynaecological cancers." Sally Fawkes

### **Our Volunteers**

Women with a personal experience of breast or gynaecological cancers are the heart and soul of BreaCan...

- Collective action of women enabled the establishment of the service.
- Peer support is a core element of the BreaCan service model.
- Many women support and promote the service in a growing number of roles.

In 2011/2012, the fifth intake of BreaCan peer support volunteers completed their training and orientation and now routinely work in the Resource Centre. The BreaCan volunteer pool has grown to 63 women comprising 40 trained peer support volunteers and 23 women working in a range of supporting roles. A number of those women work in multiple roles within the service. In 2011/2012, the volunteer roles included: peer support in the Resource Centre; peer support at the *Bridge of Support* at RMH; BreaCan Advisory Group membership; speaking engagements to share stories and promote BreaCan; leading and supporting group exercise programs; representing BreaCan at conferences and events; administration of the BreaCan library; supporting BreaCan mailouts and other administrative tasks.

Volunteers from the 5th intake and the then Volunteer and Services Co-ordinator Helen Shepherd (seated centre) celebrate the completion of the training program



The Volunteer Reference
Group is a good way for
volunteers and staff to build
on our everyday conversations
with each other.

Bridget, Peer Support Volunteer

As the BreaCan volunteer team has grown and evolved, we have needed to find new ways of communicating, connecting and ensuring that the voices of volunteers are heard and actively inform our service planning, delivery and improvement. The BreaCan Volunteer Reference Group was formed in May 2012 and will provide an important link to the governance of BreaCan. Membership is open to all volunteers and a flexible and inclusive approach has been taken in its development.

We thank the women who have volunteered for BreaCan in 2011/2012 for their generous contributions:

#### Peer support trained volunteers

Aaltje, Ang, Ange, Annette, Barbara, Betty, Bridget, Carolyn, Chris, Cindy B, Cindy SF, Dianne, Ellie, Ellen, Florence, Frederika, Georgina, Heather, Helen, Janine, Jill, Joan, Joy, Jules, Kirsten, Leanne, Mary, Meril, Nikki, Pam, Paula, Pauline, Rhonda, Rita, Sandra, Sue, Suzanne and Teresa.

## Other women who volunteered for BreaCan in 2011/2012

Bev, Carolyn, Cheryl, Claudia, Dorothy, Elizabeth, Jocelyn, Judy, Jewels, Lois, Maureen, Naideen, Patricia, Sandra, Sue E and Sue S.

Peer support volunteer Paula gets into the Christmas spirit at the annual end of year volunteer celebration



## **Looking Forward**



Women celebrate at the annual BreaCan end of year morning tea

BreaCan is at an exciting phase in its growth and development. With increasing demand for the service and consistent growth in a number of areas, there are many opportunities to further extend our reach and accessibility of the service for Victorian women, their partners, family members and friends. In 2012/2013, we will:

- Finalise a three year strategic plan to guide our work from 2012 to 2015
- Develop some key strategies to underpin service growth and development including a communication strategy, a plan to grow our funding base and a diversity strategy to guide our work to improve accessibility of the service for all women
- Continue to build and diversify our volunteer workforce through a new intake of peer support volunteers and through formalising a range of other volunteer roles and associated training requirements to support and extend the capacity of the service



We will continue to build and diversify our volunteer workforce through a new intake of peer support volunteers and through formalising a range of other volunteer roles. Alison Amos

#### **Thank You**

BreaCan would like to say thank you to all the people and organisations who have donated time and/or resources to BreaCan during the past year.

We would also like to thank all the women, their families and friends who have used the service over the past year and been involved in helping us continue to provide a quality service through their comments, feedback and stories.

- Continue our important project partnerships to increase access to our services for women with gynaecological cancers and improve transitions to 'survivorship' for women at the end of active treatment
- Seek funding to maintain the *Bridge of Support* at the Breast Service of the Royal Melbourne and Royal Women's Hospitals and explore the potential to extend the service to women with gynaecological cancers having treatment at the Women's
- Seek funding to develop a Bridge of Support service model tailored to the needs of women undergoing treatment at Western Health
- Improve access to our services through the introduction of new information and communication technologies to connect with women who are unable to travel to a city-based support service and through community forums in regional Victoria
- Strengthen our data capability with implementation of a tailored client and volunteer
  management system to improve the quality and accessibility of data, streamline service
  provision and enhance our capability to monitor, evaluate, improve and report on our
  service performance
- Continue to build productive relationships with the cancer, research, volunteering and consumer participation sectors to support and extend our capacity.

## **Our Supporters**

In 2011/2012 many individuals, companies and organisations have made generous financial and service related contributions to help BreaCan deliver the best service possible to Victorian women. We are extremely grateful to the following:

#### **Donors**

Regina Armstrong
Robynne Berg
Jennifer Burrows
Carlene Charlton
Kathrin Davenport
Michele Day
Cinthia Del Grosso
Anita Dickons
Suzanne Douglas
Frances Emerson
Ellen Fahmy
Sue Foster
Jane Galbraith
Katherin Grellis

Enid Harlock
Coral Harlock
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Sandra Moore
Susan Moore

Maree Mursell
Imelda Palmer
ess Peggie Payne
Violet Powley
ght Jill Price
Maren Rawlings
Christine Ricketson
all Alistair Ruffell
Denise Ryan
Di Sellenger
Linda Sim
Helen Smythe
Rachel Stafford
Maureen Staveley

Clare Barrett

Faith Styles
Meike Suggars
Rhonda Tilley
Charmaine Townsend
Deborah Wilson
Poppy Wilson
Beverley Wong
A group of ladies
from Vermont South
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Creation
Embracing Racing
The Forget-Me-Nots
G.R.A.C.E. Support
Group

Hamish Farrow

Grill'd Healthy
Burgers – 'Local
Matters' Program

Microsoft
Corporation
Oaks Day Luncheon
Portland Shutters
and Blinds
The Young Ones
Virtual Enterprise
Australia
There were
also donors who
wished to remain
anonymous.

#### **In-Kind Donations**

Belinda Astl Clare Barrett Anne-Maree Bortoli Ionathan Cebon Richard De Boer Hamish Farrow Pat Mazlin Tara McKinty Sofie Mikosa Leanne O'Sullivan Libby Oldfield Genesis Fitness Club Monash University IT students National Australia Bank volunteers RMIT Masters in

Marketing students

#### Friends of BreaCan

Fernwood Gym Yarraville IceLabs IT Strategic Knowledge Base Systems La Bella Design Living Well Services Sheila Hirst Consulting Squisito

### Presenters of Group Sessions

Iane Fletcher Jennie Bendistinto Craig Hassed Anne-Maree Bortoli Martha Hickey Sue Bowles David Bowtell Caren Hudson Adele Hulse Margie Brett Esther Briganti Jane Jeffers Catherine Kelly Christina Carlyle-Taylor Kay Kilham Jonathan Cebon Vlado Krstevski Mitchell Chipman Jeremy Limpens Liz Crocker Debbie Ling Barb Cummins Tara McKinty Sally Dawson Gabrielle McMahon Richard De Boer Sofie Mikosa Justine Diggens Derek Neoh Lynda Evans Emma O'Brien

Libby Oldfield
Leanne O'Sullivan
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Jeremy Prentice
Judy Purbrick
Kym Reid
Sheryl Roach
Kirsty Rollason
Adrienne Stephens
Blaise Van Hecke
Sara Van Hecke
Judith Woods
Mary-Anne Young
Les Zigomanis

Veronica O'Dwyer

# Help BreaCan reach more women

In 2012/2013, donations will continue to support our fortnightly foot reflexology sessions, rural forums and to enable us to offer assistance to women in financial distress. With the support from donations, we also hope to secure sufficient funding to expand the *Bridge of Support* program to other hospitals in Victoria.

Give now to help us grow.

Yes, I would like to donate a gift by cheque to BreaCar
Please make cheques payable to BreaCan

Yes, I w	vould like	e to mak	e a dona	ation usin	g my cr	redit	card
\$10	\$20	\$50	\$100	Other a	mount S	5	

Mr	Mrs	Ms	Miss	Other	 
Given (fi	irst) name				 
Surname	e				 
Address					 

State . . . . .

Postcode . . . . . .

Signature .....

I give permission for my name to be included in BreaCan's *Year in Review* as a donor

If you would like to discuss other ways of helping BreaCan, please phone 1300 781 500. All donations over \$2 are tax deductible (address or email required for receipt). Mail to BreaCan, GPO Box 1066, Melbourne VIC 3001.



# extend our service capacity

In 2011/2012, BreaCan received \$26,698.25 in donations.

Included in this total was a specific donation of \$14,255.54 received from the 'Young Ones' breast cancer group. This funding is supporting a young women's project that has commenced and will continue in 2012/2013 exploring and seeking to respond to the unmet needs of young women with breast cancer.

Other donations received by the service in 2011-12 allowed us to offer:

- 110 foot reflexology appointments
- Two rural forums:
- one in Geelong in May attended by 55 women
- one in Sale in June attended by 38 women
- Two Auslan interpreters to support a deaf woman to fully participate in the Sale forum
- Financial assistance for four individual women experiencing financial distress requiring immediate assistance with accommodation costs, bills and the purchase of bras.

PHONE 1300 781 500 FAX (03) 9921 0840 EMAIL breacan@breacan.org.au WEBSITE www.breacan.org.au PODCASTS www.breacan.org.au/services-events/ information-sessions/archive

#### **BREACAN RESOURCE CENTRE**

Ground Floor Queen Victoria Women's Centre 210 Lonsdale St Melbourne VIC 3000

**HOURS OF OPERATION** Monday 10am-2pm Wednesday 10am-2pm Thursday 10am-2pm (Closed Public Holidays)

The Bridge of Support at the Royal Melbourne Hospital operates on alternate Tuesdays (12-4pm) and Thursdays (10am-2pm).



#### **POSTAL** GPO Box 1066 Melbourne VIC 3001







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Subscribe to our e-What's New and e-What's On at http://breacan.org.au/get-in-touch/join-the-mailing-list

#### **OCTOBER 2012**

DESIGN: Lin Tobias/La Bella Design LAYOUT: Lorna Hendry TEXT: BreaCan PRINT: Adams Print STOCK: 150asm Revive Pure Silk



BreaCan is a service of Women's Health Victoria www.whv.org.au

BreaCan is funded by the Victorian Department of Health. COVER PHOTO: Each year the service provides a diverse range of group sessions, from Sashiko, the art of Japanese embroidery, to understanding clinical trials. It is this commitment to acknowledging and responding to the diversity within our community and people's experience of cancer that we highlight in this year's Year in Review.

QUOTES: Please note that some names have been changed to protect people's privacy. For privacy reasons we do not publish the full names of BreaCan volunteers.

