



## 15<sup>th</sup> UICC Reach to Recovery International Breast Cancer Support Conference

### One journey — many people

Brisbane Convention Centre, Brisbane 13-15 May 2009

<http://www.reachtotherecovery2009.org/>

#### Report by Kerrie Griffin

#### Introduction

Sincere thanks to Dragons Abreast ACT who sponsored my participation at the Reach to Recovery International conference. I've included hyperlinks to relevant resources for your future reference. Here is my summary of the plenary sessions and workshops that I attended which was only a small part of this enormous conference. It was difficult to choose from so many topics. Many thanks to **Bea Brickhill**, DA ACT, a recently diagnosed friend, for sharing the journey with me as well as providing her notes on the media workshop. I enjoyed meeting and mingling with many new, kind and generous people from around the world and Australia, including the ACT. It was an uplifting and challenging experience.

Link to the PDF including abstracts:

<http://www.qldcancer.com.au/reachtotherecovery2009/conference/documents/ProgramBook>

The theme *One journey many people* was echoed throughout the Reach to Recovery conference by all the keynote speakers. It is particularly poignant that it was the idea of **Lyn Moore**, DA Brisbane and long time BCNA Queensland Representative.



Kerrie Griffin, Gillian Horton (Bosom Buddies BCNA Liaison); Barb, DA Bryon Bay; Alison Meretini and Jacki Spence, ACT Cancer Council and Lyn Moore, DA Brisbane and BCNA Queensland

*You are not alone* was a recurring theme as inspiring speakers spoke of the amazing research and support networks happening around the world. The plenary and workshop speakers were professionals of a very high calibre who were able to translate complex research findings for the layperson in a relevant and succinct fashion.

Professor **Jeff Dunn**, Conference Chair and CEO Cancer Council Queensland, spoke of the infectious buzz at any breast cancer meeting but especially at this conference as women networked and shared support. He said the conference had the international spirit of common goals, working together with health professionals, governments, community, and colleagues from support organisations. 'This conference gave women affected by breast cancer the opportunity to build new support networks with other women from all over the world. It empowers women to take action to raise awareness of breast cancer in their local communities.'

I must acknowledge the outstanding Conference organisers, **Queensland Cancer Council** and wonder woman **Megan Dwyer** (Amazon Heart cofounder).



Lyn Swinburne CEO BCNA; Glenise Webb, and Natrasska Chiron Bosom Buddies; Gertrude Nakigudde, Uganda Women's Cancer Support Organization; Lyn Moore and Kerrie Griffin at the pink Parliament House reception



Kerrie Griffin, Lily, Malaysia; Mornington Peninsula members including ; Gail, Jo Lovelock, Amazon Heart (far right) at the pink Parliament House reception

### Conference networking highlights

Conference highlights included many networking opportunities to meet some of the 600 plus delegates. We enjoyed a pink **Welcome Reception** at Parliament House on Tuesday evening after the preconference workshop on Indigenous art. We had fun at the **Adventure Workshop** at Riverlife on Wednesday. I chose Indigenous dance in order to meet international visitors but I also gained insight from the Indigenous dancers as they answered questions that no Australian would ask (like where are the women dancers)! It was a mutually empowering and beneficial experience. We stayed for the BBQ and watched the sunset, then stars, as we sat near the river on a clear and perfect night and returned by ferry. I caught up with a few at the young women's drinks at the Fox Hotel afterwards.

On Thursday evening, many wore impressive national dress to the **Conference Dinner** at the beautiful old sandstone Brisbane City Hall. We applauded the international and Australian award winners including **Sandra Gregg**, a Queensland breast care nurse and trainer, won first prize in the 2009 AstraZeneca Breast Cancer Care Award and **Dr Fran Boyle AM** who received a commendation. **Meredith Campbell** (Amazon Heart cofounder) received an award for her vision, inspiration and drive for the conference. We were entertained by the *Breast Wishes* crew <http://www.breastwishes.com.au/> and danced till the end under the blue luminous dome to a great young swing band.



Conference Dinner venue, Brisbane City Hall



Malaysian delegates; Michael Connolly, Indigenous artist; Natrasska Chiron and Lyn Moore with the cooperative painting including dragon boats painted at the preconference workshop

We enjoyed and joined in with the 45 Taiwanese delegates who gave an enthusiastic singing and dancing performance, screen presentation and gifts to encourage attendance at the next Reach to Recovery International Conference to be held in **Taipei from 9 to 12 November 2011**. Each morning, we had the opportunity to have breakfast and enjoy tai chai (day 1) or yoga (day 2) at 8am. Following the conference, some paddled with DA Brisbane and visited a jazz festival. The following week, Megan and Meredith organised the **Amazon Heart Thunder** Brisbane to Sydney trip with 39 Harley Davidson trail blazers for a motorcycle ride of a lifetime.

### Day 1: Survivorship

Plenary 1.1 The opening was spectacular with an Indigenous dance troupe's welcome to country, fire making and a smoking ceremony to cleanse the delegates. Four **Amazon Heart** members rode their Harley Davidson motorcycles into the conference centre to deliver the message stick; which travelled around the world on a journey of hope connecting breast cancer survivors and drawing delegates to Brisbane for the conference. <http://www.themessagestick.com/message.php>

Plenary 1.3 Professor **Anne Stanton**, UCLA, USA, provided an insight into her research into psychological and physical health and what helps or hinders women confronted with breast cancer. She looked at the power of transformation and how some women are bolstered and develop resilience and find benefits and strength through relationships, enhanced appreciation of life, reassessed priorities, spirituality and health-promoting behaviour. It takes a year to recover from chemotherapy and the highest psychosocial risk is with younger and/or isolated women with chronic stresses. [http://cancercontrolplanet.cancer.gov/breast\\_cancer.html](http://cancercontrolplanet.cancer.gov/breast_cancer.html)

Plenary 1.4 Professor **Cheng Har Yip**, Kuala Lumpur, Malaysia, (who was awarded the top Reach to Recovery award at the dinner) focused on the global patterns of breast cancer incidence, trends and treatment; based on her research in the epidemiology, early detection and management of

breast cancer in developing countries. The introduction of a Western lifestyle and diet in developing countries increases the risk of breast cancer. For instance, in Malaysia the rate is 1 in 20 women; with women presenting with more advanced tumours and using joss ticks or burns as traditional treatment. A major fear is that men will abandon them as women are not decision makers in their culture, ethnicity and religion. HIV/AIDs, not breast cancer, is the major health concern that leads to conflicting priorities. [Breast Health Global Initiative](#) is working towards evidence-based, economically feasible and culturally appropriate support, advocacy, awareness, education, sharing and empowering women in order to close the gap.



A tai chi class before breakfast with Glenise Webb, Vice President, Bosom Buddies and other early birds

Workshop 1.4 *The Survivorship: Quality of life after breast cancer* workshop drew a full house and probably should have been a plenary session.

**Anna Hawkes**, Cancer Council Qld, outlined the current recommended balanced diet and regular exercise program and indicated that people should try to be lean, not smoke, exercise 30 minutes daily, eat dietary fibre, limit red meats, avoid processed meats and drink in moderation (one drink daily; two alcohol free days = five drinks per week). Dietary supplements are not recommended. Obesity, alcohol consumption, being inactive and smoking are still the main lifestyle risk factors.

*Author's note:* Nevertheless, these criteria do not apply to so many of my friends when diagnosed with breast cancer. Please don't blame the victim — more research is required.

<http://www.cancer.org.au/Healthprofessionals/patientfactsheets.htm>

Something for partners:

[http://www.cancer.org.au/File/HealthProfessionals/Factsheets/F\\_S\\_EarlyDetect\\_Prostate.pdf](http://www.cancer.org.au/File/HealthProfessionals/Factsheets/F_S_EarlyDetect_Prostate.pdf)



Happiness was infectious at the Pink Parliament House



Ellen Weaver (left) and Sue Bowen (right), DA Brisbane; at the Indigenous workshop at Riverlife

Dr **Susan Carter**, Rocky Mountain Colorado, showed an inspiring PowerPoint presentation on the benefits of exercise in cancer rehabilitation. Her research found that exercise is empowering and increases energy, improves body image and acts like an anti-depressant medicine. A water treadmill was developed for people with fractures and at risk of bleeding. Exercise during chemotherapy is beneficial for the heart. <http://www.unco.edu/rmc/ri/>

Professor **Afaf Girgis**, CHeRP, (who has an international reputation in cancer prevention and early detection and was an early supporter of the formation of BCNA) outlined the results from the Australian study on *Lifestyle behaviours and future health promotion priorities for breast cancer survivors: the 45 and up* study cohort. These results informed the recent NBCF Think Tank\* on program research to identify priority areas, such as physical activity and healthy eating; and to evaluate research and evidence on the five year benchmark after cancer. It appears there is a 'teachable moment' which motivates women to stop smoking and participate in breast screening. The statistics change after 10 years (since the diagnosis of breast cancer) when women start to consume more alcohol. The average age of women surveyed was 61 years. The challenge is how to reach socially disadvantaged groups. \* [REVISING NATIONAL ACTION PLAN](#)



Bea Brickhill, Cathie Lockenwitz, Denmark; Kerrie Griffin and friends at the Pink Parliament House reception



Ritu Joseph-Bryant, India; Malaysian delegates and Mary Onyango, Kenya; at the Pink Parliament House reception

**David Shum**, Griffith University, talked about chemo brain and took us through the cognitive functions of the brain (speed of information processing, attention, memory, language, executive functions, visuo-spatial reasoning) and acknowledged other factors (eg motivation, depression, anxiety). He looked at 15 studies since 1995 on thinking straight after chemotherapy and decided that more research needs to be done on chemo brain; the audience agreed enthusiastically.

Questions arose from this session about alcohol consumption (binge drinking is not encouraged); what research has been done into stress; what are 'normal' and manageable stress levels as well as the potential possible benefits of preventative exercise for women with BRCA1 or BRCA2 genes.

## Day 2: Capacity building

### The sounds of silence Simon & Garfunkel

'Fools', said I, you do not know  
 Silence like a [cancer](#)  
 grows.  
 Hear my words that I might teach you,  
 Take my arms that I might reach you.  
 But my words like silent raindrops fell,  
 And echoed  
 In the wells of silence

Plenary 2.1 [Stella Kyriakides](#), President, [EUROPA DONNA](#) Cyprus, spoke on breaking the sounds of silence by maintaining the momentum and supporting lobbying and advocacy about breast cancer. Our collective actions for patients' rights are dynamic and can break down the stigmas, taboos and fear (eg fear that breast cancer is contagious) by educating and changing attitudes to give dignity to individuals. Stella, a survivor, encourages partnerships such as with breast care nurses and multidisciplinary teams. Stella urged for equal access to care and treatment worldwide. Europa Donna Cyprus has introduced an annual Field of Women walk where women carry pink silhouettes inspired by the BCNA Field of Women (despite few gardens in Cyprus!). Some may

remember Stella talking at the BCNA 2<sup>nd</sup> National Conference in 2004 (*Still Making a difference — Still MAD*) when she was President of Europa Donna. She is now an MP in Cyprus.

Plenary 2.2 **Mary Onyango**, Kenya Breast Health Program, spoke about the challenges in African countries where life expectancy is only 47 years for a woman. Breast cancer is increasing but usually detected at a later stage as there is no organised country screening. HIV/AIDs, not breast cancer, is a major problem. Due to poverty, the healthcare system is often informal and traditional treatment is used. There is an enormous need for public education campaigns and healthcare training for standard diagnosis and treatment, pathology and data collection. <http://www.kenyabreast.org/>

We were very lucky to have 14 inspiring and positive country delegates who were sponsored by major organisations. Hope is held out for the [Breast Health Global Initiative](#) (BHGI) which strives to develop, implement and study evidence-based, economically feasible, and culturally appropriate *Guidelines for International Breast Health and Cancer Control* for low and middle income countries to improve breast health outcomes.



A Caribbean delegate and Mary Onyango, Kenya, learn boomerang throwing at Riverlife

Plenary 2.3 **Marion Morra**, American Cancer Society, spoke on the urgency for capacity building worldwide as two thirds of cancers are preventable or treatable if detected early. The United Nations' World Health Organisation's 2015 goal is to reduce cancer deaths by 7.7 million. [http://www.cancer.org/docroot/lm/lm\\_0.asp](http://www.cancer.org/docroot/lm/lm_0.asp)

Plenary 3.1 **Mollie Williams**, works for the [Susan G. Komen for the Cure](#), USA, which is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energise science to find the cures. It invests in programs that save lives and reduce disparities throughout the continuum of care, including screening, diagnosis, treatment, and survivorship.

An essential part of their strategy is the community profile, a needs assessment, that affiliates conduct every two years to understand who in their community bears the greatest burden of breast cancer. The community profile and asset map build their capacity to develop and implement effective programs. [San Antonio Breast Cancer Symposium](#)



Kenya delegates including Mary Onyango, Kenya, Kerrie Griffin, Gerda Evans, BCNA and DA Melbourne, at the BCNA stall

Plenary 3.2 **Sue Murray**, CEO National Breast Cancer Foundation, **Lyn Swinburne**, CEO Breast Cancer Network Australia and **Helen Zorbas**, CEO National Breast and Ovarian Cancer Centre, spoke about Australian national breast cancer organisations working together. They highlighted practical examples of collaboration and the effective relationship developed across the three organisations, which have resulted in genuine improvements for women with breast cancer. They work separately and together to improve breast cancer outcomes through:

- High quality and coordinated research into treatments, care and ultimately a cure
- Evidence-based, quality information for those affected, their families and their health care professionals
- Improved care and treatment outcomes for those diagnosed
- Access to decision-makers and support for those who have trodden the same path.

**Breast Cancer Network Australia (BCNA)** is the peak national organisation for Australians personally affected by breast cancer. BCNA empowers, informs, represents and links together people whose lives have been affected by breast cancer. BCNA works to ensure that women 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. BCNA is represented by the Pink Lady silhouette, which depicts our focus; the women diagnosed with breast cancer. [Mini-Field Ideas](#)

Dragons Abreast, Bosom Buddies, Encore and BreastScreen are among BCNA's 220 member groups. Any individual can join for free and receive

[The Beacon](#) ([Subscribe](#) quarterly) as well as online ebulletins.

Order [online](#) or call 1300 78 55 62 to order your free *My Journey Kit* for women with newly diagnosed breast cancer. [Annual Report \(Natrasska Chiron](#) at the Calvary Healthcare BCNA Mini Fields of Women, October 2007 is on the front cover). Join the Review & Survey Group now! [Fact sheets](#) [www.bcna.org.au](http://www.bcna.org.au)

**National Breast and Ovarian Cancer Centre (NBOCC)** is Australia's national authority and information source on breast and ovarian cancer. Funded by the Australian Government, NBOCC plays a lead role in national cancer control and improving cancer care through an evidence-based approach to informing best practice, health systems' reform and policy. NBOCC works in partnership with health professionals, cancer organisations, researchers, governments and those diagnosed to improve outcomes in breast and ovarian cancer.

As part of its commitment to 'closing the gap' in breast cancer outcomes for Indigenous women, NBOCC is working in collaboration with Indigenous leaders, communities and networks to promote the importance of early detection in surviving breast cancer.

[Order resources](#) such as the newly revised [Guide for women with early breast cancer](#) [www.nbocc.org.au](http://www.nbocc.org.au) <http://www.nbocc.org.au/lymphoedema/> <http://www.nbocc.org.au/resources/nboccnews/April09.html>



Malaysian delegates, Lyn Moore, MISSABITTATITTI, dressed for the DAA workshop and Kerrie Griffin at the think pink stall

**National Breast Cancer Foundation (NBCF)** is the leading community-funded national organisation raising money for research into the prevention, detection and treatment of breast cancer. Research programs funded by the NBCF cover every aspect of breast cancer, from increasing understanding of genetics to improving ways to support women and their families. NBCF is a not-for-profit and was established in 1994 and has allocated over \$55 million dollars to over 230 breast cancer research projects throughout Australia. [FAQ](#) [www.nbcf.org.au](http://www.nbcf.org.au)



Conference dinner, Brisbane City Hall

Since the formation of NBCF death rates have been falling. This is as a result of improvements in treatment and early detection all of which have evolved from high standards of research both in Australia and internationally. Despite these advances, there are many aspects of breast cancer which are still not understood, particularly the causes of breast cancer.

Research showed that early detection of breast cancer through mammography helps to save women's lives. Research also produced new knowledge of the best way to treat breast cancers using chemotherapy and hormones.

*The combination of early detection and better treatment has led to a steady reduction in the death rate from breast cancer since 1994.*

*Workshop 2.2 Consumer involvement in research: A priority setting workshop with **Sue Carrick**, Head of Research Strategy, NBCF and **Afaf Girgis** looked at the positive impact of consumer participation in reviewing research priorities and funding since 1996. The six key areas include the extent of the benefit, pathway for realising the benefit, potential application of findings, equity, consumer involvement (in the development phase and ongoing) and the dissemination of research results in a best practice environment. There are challenges such as the difficulty in working with consumers (accepting opposing or outspoken views), giving feedback and recognition, assessing consumers, practical and time constraints, cost, clarification and negative or complacent attitudes towards consumer involvement.*

**Leonie Young**, (breast cancer survivor since 1987), Consumer Coordinator, IMPACT (Improving Participation and Advocacy for Clinical Trials, ANZ Breast Cancer Trials Group) spoke about the benefits in being involved in the process. Since 1999, consumer advisory panels have broadened the perspective and helped review research protocols. Both Afaf and Leonie were active in the 1996 committee which led to the formation of BCNA.



Indigenous dancing workshop at Riverlife

Workshop 2.5 *Health and the media* Thanks to **Bea Brickhill** for her notes.

**Anne Savage** suggested paying attention to the news environment; connecting with the people you represent and having a clear objective in mind. Brochure outline:

- Use case studies as journalists are looking for the human angle
- Target the right journalist such as health, community or feature writers interested in your story
- Be resourceful and helpful even if you don't have the information as they may call you next time when you do have more resources
- Be available, prepared and return messages as soon as possible; ask for their deadline
- Use local media and match the story of a local person to it
- Get to know journalists personally as they are more likely to call you when they need a quote on an issue
- Use a creative subject headline to ensure that it is read and not deleted
- Consider the best way to make contact. Don't phone after a media release has just gone out as they will contact you if they require more information. Ensure it is clear, interesting and relevant to their work. Be proactive in pitching new, exclusive ideas over the phone first, then email the details
- Do your research on the type of features, who writes them; think about format, style and content to get your message to fit in the specific publication
- Be aware of the media by contacting journalists and finding out what type of stories they are after, their deadlines and what works best for them.

*How the media works: A journalist's perspective by **Jill Margo**, Walkley Award-winning journalist, *The Australian Financial Review*. Jill said health is a highly prized topic in the media and content is the key. There is an insatiable appetite in the media for interesting health stories.*



Kiraley LaTour, New York, with her mum Kathy LaTour, Texas; Wanda, Washington; Bea Brickhill, Juliette, NZ; and Bonnie, Washington Amazon Heart, at the BBQ, Riverlife

**Breast cancer in the media Kathy LaTour**, [www.curetoday.com](http://www.curetoday.com), the largest direct to patient cancer magazine in the USA, provided tips and approaches to obtain coverage for breast cancer events, messaging, and breaking news. The media are looking for something that:

- Is new as they all want to be first
- Affects the community and notable people
- Has conflict
- Uses superlatives such as biggest, only, first, last and statistics
- Uses a tagline that has impact, eg Field of Woman
- Uses colourful stories about real women
- Tells credible experiences and provide appropriate materials.



Barb, DA Byron Bay, Terry Mitchell, Canada, the unflappable Lyn Moore, Brisbane and Kerrie Griffin on the way to the ferry

**Workshop 3.5 Reach to Recovery: approaches to wellness**  
*Team training as a predictor of reduced recurrence among breast cancer survivors participating in survivor dragon boating*

**Terry Mitchell**, Director of the Centre of Community Research Learning and Action and Associate Professor, Department of Psychology, Wilfrid Laurier University, Waterloo, Ontario Canada (near Peterborough)



Ellen Weaver, Sue Bowen and Rosalie Thomas, DA Brisbane MISSABITTATITTI at the DAA stall

This was one of the most exciting research presentations. Terry's findings on women who did regular exercise with their dragon boating team\* showed they had a lower rate of recurrence than women who exercised alone (\*two or more times weekly to a high degree). The intensity of paddling was not specific as it was not measured but rather the holistic engagement with the team and paddling. The group dynamics gave women the emotional strength to regain their body image, confidence and sense of accomplishment and shift priorities. It gave them permission to focus on themselves instead of others (ie they had to go to training so they didn't let the team down). They suffered less stress and trauma than other women with breast cancer post treatment. Their improved quality of life was not related to the stage of illness. *Look out for this research paper on the Dragons Abreast website soon.*



Terry Mitchell, Canada and Kerrie Griffin with Indigenous dancers at Riverlife

**Workshop 3.6 Taking control: Managing end of life issues**

**Dr Ednin Hamzah**, Malaysia, said although the World Health Organisation has advocated that palliative care be included in national cancer programs, many governments and health care planners do not give it the same emphasis as other

aspects of cancer control. Despite palliative care being recognised as a medical specialty, it is dogged by misconceptions and assumptions. *Author's note:* Once again, my western sensibilities were challenged by very daunting and confronting images of late stage, external, horrific body tumours that are regularly found in developing countries.

He also showed a moving case study on a 28 year old young wife and mother as she battled existing prejudices in Malaysia. Initially, when she was diagnosed she followed traditional treatment as encouraged by her mother. After a year, she returned to the doctor to discover her tumour had grown 12 cm and she was treated medically for secondary breast cancer. Her husband was violent and she blamed herself for bad karma for having breast cancer. She planned a trip to Mecca to cleanse her soul but her husband would not allow her to go. She struggled to look after her family during further treatment and finally died leaving a young family.

A model of care focused on a curative aim rather than quality of life may fail to address the needs of many; especially those with advanced disease. Yet, when palliative care addresses these issues, by making improvements in their quality of life, many patients value it. Palliative care should be integrated within the whole paradigm of breast cancer care.

**Jill Margo** spoke about her book, *Living on*, and website [www.myheartwill.com](http://www.myheartwill.com) where you may leave a legacy of personal experiences for loved ones. [The heart will - Health Report - 5 May 2008](#)  
*Author's note:* From a practical perspective, with rapid changes in modern technology, I found this difficult as the online environment continually changes so much.

Instead, for a very inspiring and moving account of handling practical issues with love and encouragement, please see last page iv in link 13 below by **Julie Hassard**, former Policy and Programs Manager, BCNA, about her sister, Jac's legacy to her three young children.

**Jac** passed away in April 2009 and Julie is now working part time for BCNA:

After preparing the memory boxes, Jac said that she felt at peace and happy she has done all she could to leave Ebony, Grace and Lochie wonderful words, gifts and memories. We know they will be treasured throughout their lives.

[The Inside Story 13: 'Helping friends and family to help you' 255.32 Kb.](#) [The Inside Story](#)

[www.winstonswish.org.uk](http://www.winstonswish.org.uk) a UK-based service for bereaved children is also recommended by Julie.



Making fire at the Indigenous dancing workshop at Riverlife

**Deborah Prior** spoke about the holistic palliative care approach and how minority cultural groups, such as Indigenous people, are under represented due to inequities of access including misunderstanding about the intentions of palliative care, racism, language and literacy differences, culturally different perceptions, lack of minority staff and inaccessible services in rural and remote communities. She urged for a capacity building approach to increase access to palliative care for Indigenous people in Australia.

[The Final Journey](#)

BY KATHY LATOUR

[Calming Cancer Pain](#)

[Web Exclusive: A Granddaughter's Eulogy](#)

[Web Exclusive: Understanding Hospice](#)

[Web Exclusive: Resolving Your Own Death](#)

[Web Exclusive: What Is a "Good Death?"](#)

[Audio Slide Show:](#)



Gold Coast delegates with Kerrie Griffin ready for tai chi

### Day 3: Peer support

<http://www.reachtoerecovery2009.org/>

Plenary 4.1 *Depression and Anxiety and Breast Cancer* **Suzanne Chambers**,\* GM Research, Cancer Council Queensland, [Beyond Blue](#) said that the risk among cancer patients getting depression was three times higher. The highest risk factors for women with breast cancer are: lower socio-economic status, more advanced disease, fatigue or being younger. Any previous history of depression or low optimism; poor social support



and low perceived level of control with a tendency to self blame and negative perceptions are also factors as well as poor problem solving ability, sedentary behaviour and low life goals and/or values. Targeted strategies include screening for risk and distress and referrals for appropriate help. The intervention should be a tiered model with psychosocial care to promote exercise and provide opportunities for personal growth to nourish and sustain and build resilience. BCNA's [The Depression and Breast Cancer Fact Sheet](#). \*Meredith Campbell's sister

Plenary 4.2 *The impact of breast cancer on the family* **Jane Turner**, Psychiatry, University of Queensland. There is unspoken family stuff around diagnosis and complex treatment; and often the partner feels left out, isolated and helpless. The children feel unhappy with too little information which compounds the distress and uncertainty. A third of children felt that their parents did nothing to help them cope. No child can walk between the raindrops. Jane says there are resources out there such as the BCNA *Hope and Hurdles pack* for women with secondary breast cancer [Read about and order](#) . Also go to [www.nbocc.org.au](http://www.nbocc.org.au)



Indigenous dancing workshop at Riverlife

Plenary 4.3 *Peer support: Reach to Recovery International model* **Ann Steyn**, South Africa, President, Reach to Recovery International. Ann spoke about the 14 delegates from African countries sponsored at the conference. Ann urged all delegates to take back knowledge of how to offer both emotional and practical peer support. The prime objective is to offer psychosocial support to breast cancer survivors to help them cope and improve their quality of life. RRI supported this aim by holding a preconference workshop on survivorship and psychosocial care which 47 breast care nurses participated in.

Workshop 4.1 *Sexuality and intimacy after breast cancer: Surely you have more important things on your mind!* **Amanda Hordern**, Cancer Council Victoria. This was a packed house and we knew something special was happening when we saw all the different coloured feather boas decorating the room. Amanda is a very inspiring and funny woman who was the first breast care nurse in Australia after developing the program. She went on to study sexuality in her PhD after a chemo patient (circa 1998) asked her when was it safe to have sex

again (approximately 48 hours); no one knew at that time. The other nurses responded with surely you have more important things on your mind!

There is a taboo on sex and cancer and the expected focus is on survival. Sexuality and intimacy are affected by cancer and 67 per cent of women with breast cancer experience some problems; 56 per cent after five years still have difficulty with reduced libido, arousal, orgasm and/or pain. Issues include early menopause and fertility in younger women is compromised by 10 years. The brain is the most important sex organ. Amanda suggested finding time for intimacy (not just sex) and making a regular date with our partner. Some practical suggestions included silicone-based lubrication such as Pjur or Astroglide as well as Sylk (kiwifruit). She recommended pelvic floor exercises to increase the blood flow to vaginal tissue which naturally ages and thins in all women. It was a feel good workshop and Amanda recommended [Passionfruit - The Sensuality Shop](#) in Melbourne which isn't seedy but an open, creative and humorous outlet that celebrates sex and sensuality in all its forms. There are new guidelines to managing hot flushes. Fantasy is recommended in chronic illness. More research is needed in all areas.



Taiwan Breast Cancer Alliance singing and dancing 'slapping the love' at the closing ceremony

Plenary 5.1 [LIVESTRONG Global Cancer Campaign](#) Lance Armstrong Foundation (LAF) **Andy Miller** spoke about the **LIVESTRONG Global Cancer Summit in Dublin, Ireland • August 24-26, 2009**. LAF is making a commitment to fight cancer. The global community is coming together to make commitments to cancer control and to provide the resources and political will necessary to achieve them. The most significant commitments will be highlighted at the Summit. Currently, cancer kills more people than HIV/AIDs, TB and malaria and will be the leading cause of death by 2010. [www.livestrong.org](http://www.livestrong.org)  
<http://livestrongblog.org/2009/05/21/livestrong-down-under-part-2-andys-journal/>

Plenary 5.2 **Sue Carrick**, NBCF, thanked and urged everyone to maintain the momentum of the advocacy movement as there is still plenty to be

done. Sue remembered being a nurse in Sydney in 1972 when she felt external breast tumours of patients and there was a stigma and taboo on the subject as still exists in developing countries today. At that time, people thought that breast cancer was contagious. Since 1994, there have been amazing inroads into education, early detection and treatment. Today, we know breast cancer is not contagious but more women are being diagnosed with it and we still don't know the causes. The conference closed with Indigenous dancing and a sense of hope and optimism. Go you good woman!



Indigenous painting with dragon boats by Michael Connolly inspired by women's stories about breast cancer at the preconference workshop

### Personal perspective

I felt as it was seven years since I was diagnosed with breast cancer that I'd been there and done that and ticked the 'C' box. I thought I was moving along the path to provide help and support for others. What a myth! Instead, the conference was an emotional rollercoaster crammed for four packed days with tears and laughter, at the same time, from dynamic and enthusiastic participants.

Advocacy is a highly organised area where women are good at bridging the gap. Much has been spent on drug companies' research but now we need to push to examine the environment. Why are so many women, born in the 1940s and 1950s, affected by breast cancer without a previous family history? We want to make a difference for younger women who are not receptive to mammograms and urgently need appropriate new early detection and treatment mechanisms. We need research on exercise and survivorship and DAA is a wonderful start. I thoroughly enjoyed all the workshops I attended but I expected more of an emphasis on environment factors and MRIs. Instead, I was haunted by disturbing images and stories about developing countries. I went looking for Dr **Susan Love's** website as she had fired me up to become a BCNA advocate at the BCNA 2<sup>nd</sup> National Conference in 2004.

### [Dr. Susan Love Research Foundation](#)

Answers to the [10 Most Frequently Asked Questions](#) About breast cancer.

Getting strong with exercise after breast cancer

<http://www.dslrf.org/breastcancer/content.asp?L2=5&L3=3&SID=173&CID=725&PID=0&CATID=0>

I was also intrigued about what we could do to bridge the gap for women in developing countries. For many years, I have supported the International Women's Development Agency (IWDA), based in Melbourne, which focuses on empowering women. A search for breast cancer didn't find any links. [Read more about IWDA ...](#)

The **Breast Health Global Initiative** (BHGI) strives to develop, implement and study evidence-based, economically feasible, and culturally appropriate *Guidelines for International Breast Health and Cancer Control* for low and middle income countries to improve breast health outcomes.

<http://www.fhcrc.org/science/phs/bhgi/>

They aim to create a collaborative force of local and international breast cancer experts and institutions to work together to achieve three main goals:

- Reduce the rate of breast cancer cases detected at an advanced stage through better coordination and expansion of ongoing outreach activities and through a national campaign to increase awareness and education on breast health.
- Develop new programs for sub-specialty training in breast cancer for different categories of healthcare providers and increase collaboration and shared information exchange among experts through the creation of the first *BHGI Learning Laboratory*.
- Increase availability of affordable and effective clinical services for the diagnosis and treatment of breast disease in Ghana and other countries.

A heartfelt thank you to all Dragons Abreast team mates and BCNA members who have helped me on my personal journey. Paddles up!

**Kerrie Griffin, Community Leader,  
Seat at the Table (SATT) Program, BCNA**



Mother's Day Classic 2008, DA ACT with Gillian Styles sweeping. *Image:* taken in his kayak by my husband, Steve Taylor, Winner of *The Canberra Times* image of the week 15 May 2009