

# bloom

Issue

**13**

August  
2012

## **Reach to Recovery International - RRI**

Reach to Recovery International is committed to improving the quality of life for women with breast cancer and their families.

# Message from Ann Steyn

President of Reach to Recovery

**I can hardly believe that we are in the last quarter of the year! How time flies when life is full of fun, love and challenges.**

This issue of Bloom is devoted to 'Issues around Sexual Intimacy and Survivorship'. Something that touches everyone diagnosed with breast cancer. Today the majority of us are fortunate enough to be able to discuss these challenges; a far cry from 40 years ago when the word sex was never mentioned in connection with breast cancer. However there are still communities where women are ostracized by their partners and family after breast cancer

An interesting article by Dr Loh Siew Yim (page 12) on sexual intimacy and survivorship with an Asian perspective shows how in traditional Asian clinics sexuality is still neglected and takes a back seat to the treatment of the disease. The article dealing with issues for low income countries (page 17) highlights the myths and fears that still exist in many developing countries.

With the development of genetic testing many women face difficult decisions. Professor Maggie Watson's article (page 7) is a reminder of the complex issues surrounding the availability of pre-natal diagnosis and pre-implantation genetic testing. Both these options raise emotional, ethical, religious and cultural dilemmas. Professor Watson details these issues and list questions that should be

asked by anyone considering them.

Also to be found in this bumper issue are articles from **LIVESTRONG**, (Sexuality and Survivorship, page 3), Breast Cancer Network Australia (Sexual well being after a diagnosis of breast cancer, page 4) and Kim Walters Choices program (Intimacy after Breast Cancer, page 5). All of them show how a diagnosis of breast cancer can impact on the sexual wellbeing/sexual relationship of women. They encourage women to ask questions and to seek information. Sexual wellbeing is crucial to long term happiness and a successful recovery.

We have two articles from newly developed support groups Faraja Trust, Kenya (page 14) and the Ortiz Gurdian Foundation, Nicaragua (page 16) which show us the important role support groups play in the recovery of breast cancer patients. An article on the new age of peer support (page 9) shows us a different form of support from the more traditional discussion based support groups!

If we can use the articles in this issue to learn more about how women feel, more about the challenges we face, more about the work that is being done by many groups, we will enrich our knowledge and skills and be better able to help those women still coming to terms with their sexuality after breast cancer. Survivorship doesn't just mean existing from day to day but living life to the full and recognizing the needs we have as women.

Email [annsteyn@reachtorecoveryinternational.org](mailto:annsteyn@reachtorecoveryinternational.org)



Ann Steyn

In other news, registration opens this month for RRI 2013, so please visit the website and take advantage of the early bird rate. And when you register, why not submit an abstract? Click here for registration details!

I hope you enjoy this edition!

**Warm Reach to Recovery greetings to you all!**

**Ann Steyn**



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### Email your submissions!

The theme of the next edition will be 'Managing distress and mindfulness'. Submissions close October 10, 2012. Please send submissions should in Microsoft Word format with any photos.

**bloom**

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Bloom is published by Reach to Recovery International. Contributions to Bloom are welcome, please email [info@reachtorecoveryinternational.org](mailto:info@reachtorecoveryinternational.org). For more information about RRI, go to [www.reachtorecoveryinternational.org](http://www.reachtorecoveryinternational.org).



We respectfully acknowledge the Indigenous women of our global community, the traditional custodians of our environment.

Reach to Recovery International is supported by the UICC and Cancer Council Queensland



# Sexuality and Survivorship



Visit  
**LIVESTRONG.org/**  
GetHelp  
for more  
information!

**Cancer can impact every aspect of a person's life - including their sexuality...**

**Fifty per cent of all adults at some time in their lives will experience sexual dysfunction, sexual problems or dissatisfaction.**

Many individuals have problems, such as gender identity issues, past memories of sexual abuse, marital dysfunction, fears of intimacy, or a whole host of difficulties that make sex painful and/or complicated, either physically and/or emotionally.

Some common examples of sexual dysfunctions are erectile dysfunction (ED), premature or retarded ejaculation, dysperunia (painful intercourse) and vaginismus (spasms of muscles at the opening of the vagina).

Examples of sexual problems are disagreements over the frequency of sexual contact, sexual behaviors, or lack of interest in sex. Struggling with sexual dysfunctions or problems frequently leads to feelings of dissatisfaction, unfulfillment, and frustration.

Many people have wrestled with sexual problems for many years before they are diagnosed with cancer. Once the cancer diagnosis has been given, sexual interest may go underground for a time, since survival becomes the priority.

Treatment, plus the demands of daily life, may take every bit of energy and attention the patient has. Some cancer treatments directly affect a patient's ability to perform sexually. Certain chemo therapies and

certainly a number of surgeries that directly or indirectly affect the sexual organs will complicate participation in and enjoyment of sex.

Chemo therapies may permanently alter fertility but they will not prevent a patient from enjoying closeness, sensual touch or sexual fulfillment.

Likewise, surgeries that affect the reproductive organs, or the body parts associated with gender identity such as breasts, may change how a person participates in sexual play, but they will not eliminate the desires for physical connection.

Sexual repercussions of various treatment options should be discussed with your physician prior to starting treatment and throughout the treatment process. Discussing sex may be difficult for many but overcoming that discomfort to get the help needed is crucial to long term happiness and a successful recovery.

Your physician or health care team members may have many suggestions on how to make sexual play more comfortable and enjoyable throughout treatment and afterwards. They can also refer you to an appropriate source of emotional support, if needed.

Those individuals who are fortunate to have had fulfilling functional sexual relationships prior to cancer, may find that being

intimate brings comfort, relaxation and an appreciation for life even during treatment and certainly after their health returns.

The individuals who have been coping with long term sexual dysfunctions or problems will have a greater challenge to overcome.

There are cancer patients who experience an increase in motivation to solve sexual difficulties as well as other problems that have been ignored in the past.

For many others, their world has been shaken to the core and they find that taking on another challenge is too much to think about and try to continue ignoring their sexual problems.

This is rarely a successful strategy since ignoring feelings produces stress and stress is implicated in causing or exacerbating ill health. It is never too late to tackle the issues in life that have brought pain, distress and unhappiness.

Even though it may seem overwhelming to get started, the benefits will be worth the efforts. Battling cancer can be inspirational so that patients thrive and flourish not just survive.

*Dale Milner is a social worker in Austin, Texas. She teaches classes on sexuality and cancer survivorship at the Lance Armstrong Foundation's LIVESTRONG Cancer Navigation Center.*

# Sexual wellbeing after a diagnosis of breast cancer

While some women experience positive changes to their sexual wellbeing or sexual relationship after breast cancer, for other women breast cancer can have the opposite effect.

*“I think the deep sense of loss and grief at the change in my sexual life needed to be mourned and acknowledged – not just the change in sexual wellbeing but the change in how I view my body and my loss of trust in my body.”*

49-year-old woman

Sexual wellbeing is a deeply personal issue, but it's a topic that Breast Cancer Network Australia (BCNA) wanted to investigate further following our 2009 sexual wellbeing research, which found there was a significant unmet need for information and support about sexual wellbeing.

In December 2010 we commissioned Professor Jane Ussher and her team from the University of Western Sydney to conduct research with Australian women with breast cancer and their health professionals. We received completed surveys from 2210 women with breast cancer from around Australia and 159 health professionals (the vast majority of whom were breast care nurses or allied health professionals).

The majority of participants (our members) told us that breast cancer had affected their sexual wellbeing, with the top five issues of concern being tiredness, vaginal dryness, hot flushes, feeling unattractive and weight gain.

*“My main problems are lack of interest and vaginal dryness. My husband is very supportive but doesn't initiate sex very often because he doesn't want to be pushy.”* 50-year-old woman

We found that while a small number of participants said they had experienced improvement in their sexual relationship through feeling closer or experiencing greater intimacy with their partner, the majority reported relationship difficulties.

*“A non-communicative relationship just got worse.”* 52-year-old woman

A number of participants said they felt that their sexual wellbeing needs and concerns were ignored by their medical team because they were seen as too young, too old, in a same-sex relationship, or not in a relationship.

Despite the majority of participants saying they had experienced adverse sexual



wellbeing changes, only 35 per cent of participants said they had spoken to someone about this.

*“Because I am not in a relationship I would find it hard to discuss my feelings of sexuality, or lack thereof.”*

67-year-old woman

The majority of participants who told us they would like to speak to someone about sexual wellbeing changes said they wanted to speak to their partner/husband. This suggests that couple communication is preferred over communication with health professionals.

It was interesting to find that even though 89 per cent of health professionals considered sexual wellbeing to be a very important issue for women with breast cancer, only 33 per cent of those who answered the survey said they always address this issue with women.

While they need to respect the choice of women to not discuss sexual wellbeing (if that is their choice), we know that some women are too embarrassed to raise the issue, or may not know what help is available. It's therefore important that health professionals raise this issue with women as part of their standard care.

*“I don't know where to go for support.”*

38-year-old woman

We asked participants if they would like information about sexual wellbeing and 68 per cent agreed that they would. The top five issues women wanted information about were: vaginal dryness, relationship

changes, difficulties in becoming aroused, hot flushes, and information for partners.

While the majority of participants said they wanted information, only 33 per cent said they had been able to find relevant information, suggesting that the information needs of women are not being met.

Breast Cancer and Sexual Wellbeing – an information resource

BCNA developed an information booklet, Breast Cancer and Sexual Wellbeing, based on the findings of this research, and feedback received from women and health professionals. The booklet aims to help women identify the issues that may affect them during and after treatment, and provides practical strategies to help assist them with:

- feeling more attractive and confident
- building emotional and physical intimacy with a partner
- building a new relationship
- the loss of desire
- the physical symptoms of menopause including vaginal dryness and hot flushes
- talking to a health professional about sexual wellbeing concerns
- finding additional information and support about sexual wellbeing.

The booklet can be downloaded by visiting BCNA's website.

Article submitted by the Breast Cancer Network of Australia - [www.bcna.org.au/](http://www.bcna.org.au/)

# Intimacy after breast cancer



## ‘Don’t be embarrassed talking about your sexuality’

**Despite the fact we now know so much more about breast cancer; that support has improved over the years; and the number of cancer survivors continues to grow, one aspect of breast cancer remains taboo: its impact on our sexuality.**

Sexuality of course is not just about sex, it is the total expression of who we are as women and is the way we relate to ourselves and others. Sexuality and more specifically, sex, is without a doubt one of the most difficult topics to discuss and studies show that if your doctor, nurse or other health professional doesn't bring it up then most people certainly won't.

As a result, cancer survivors and their partners don't access the support and information they need to overcome obstacles relating to sexuality and intimacy that cancer has brought into their lives. Interestingly, many people say they weren't prepared for the changes to their lives in this way.

Issues concerning sexual intimacy following cancer surgery and treatment are not uncommon so one of the first things to remember is – don't be embarrassed talking about sexuality issues because it's not only happening to you.

These issues can seem worse by feeling anxious about what the cancer diagnosis means for your future; changes in body image can make us feel less attractive; and depression, another subject often considered taboo, can be one more reason why these problems may exist.

With support and knowing where to find good quality and reliable information these issues can be overcome.

**Sexuality concerns can be overcome**

Low libido is one of the key areas of concern for most women following cancer treatment. Sharon Bober from the Dana-Faber Institute in Boston likens libido to a recipe with many ingredients and we merely need to work on each of the ingredients to resolve the problem.

The longer time goes by without issues being resolved, then the easier it is to not 'be in the mood'.

Of course, much is said about the differences between men's and women's attitudes to sex. It is important to remember that women who haven't been diagnosed with cancer also have similar

problems and so it is sometimes easy to blame the cancer.

A cancer diagnosis threatens our sense of self and exacerbates all other issues; sexuality and sex seem less important when our lives may be in danger. Another ingredient to the low libido recipe therefore is guilt – guilt that we may be thinking about these 'unimportant' things at such a time.

Guilt and fear can be debilitating and are emotions we need to try to eradicate from our lives to enable ourselves to be able to move forward and enjoy our lives. After all, isn't this why we go through surgery and treatments – to be able to live and therefore enjoy life!

For more information visit:-  
Breast Cancer Care UK  
Breast Cancer Network Australia

Or click here to email the Wesley Hospital Kim Walters Choices Program, Brisbane, Australia, for sexuality workshops and education for health professionals and people diagnosed with cancer.

*This article was submitted by Leonie Young and Janine Porter-Steele, Wesley Hospital Kim Walters Choices Program, Brisbane, Australia.*

[www.uhealth.com.au/choices/](http://www.uhealth.com.au/choices/)

## NEW RESOURCE:

# Improving the sexual wellbeing of women affected by breast cancer

**The ongoing effects of the diagnosis and treatment of breast cancer can be distressing for many women and their family and friends.**

For some women, one particularly challenging aspect of treatment for breast cancer can be the impact on sexual wellbeing.

However, this can be a very sensitive topic for women to raise in consultation with their doctor.

The need to provide patients and health professionals with the best support during and after treatment has led Cancer Australia to develop an online resource to better support health professionals to initiate discussions around sexual wellbeing with women and their partners following diagnosis and treatment of breast cancer.

Research conducted in 2010 by the University of Western Sydney for Breast Cancer Network Australia showed that even though the majority of women said they had experienced negative changes

to their sexual wellbeing, only 35 per cent had spoken to someone about this.

The same study showed 87 per cent of health professionals considered sexual wellbeing to be a very important issue for women during and after treatment, however few said they always addressed this issue during consultations.

The reasons cited for this difference included a lack of privacy during consultations, sensitivity to a woman's culture or religion, time constraints and pressures or because they felt that the woman may feel uncomfortable.

While a number of resources for women and their partners have been developed to provide support and information, the lack of available guidance to support health professionals to initiate difficult conversations with a patient about sexuality and relationships, was identified as an area of need.

The Cancer Australia resource will include information on issues of sexual wellbeing and identify interventions for common

symptoms impacting a woman's sexual wellbeing.

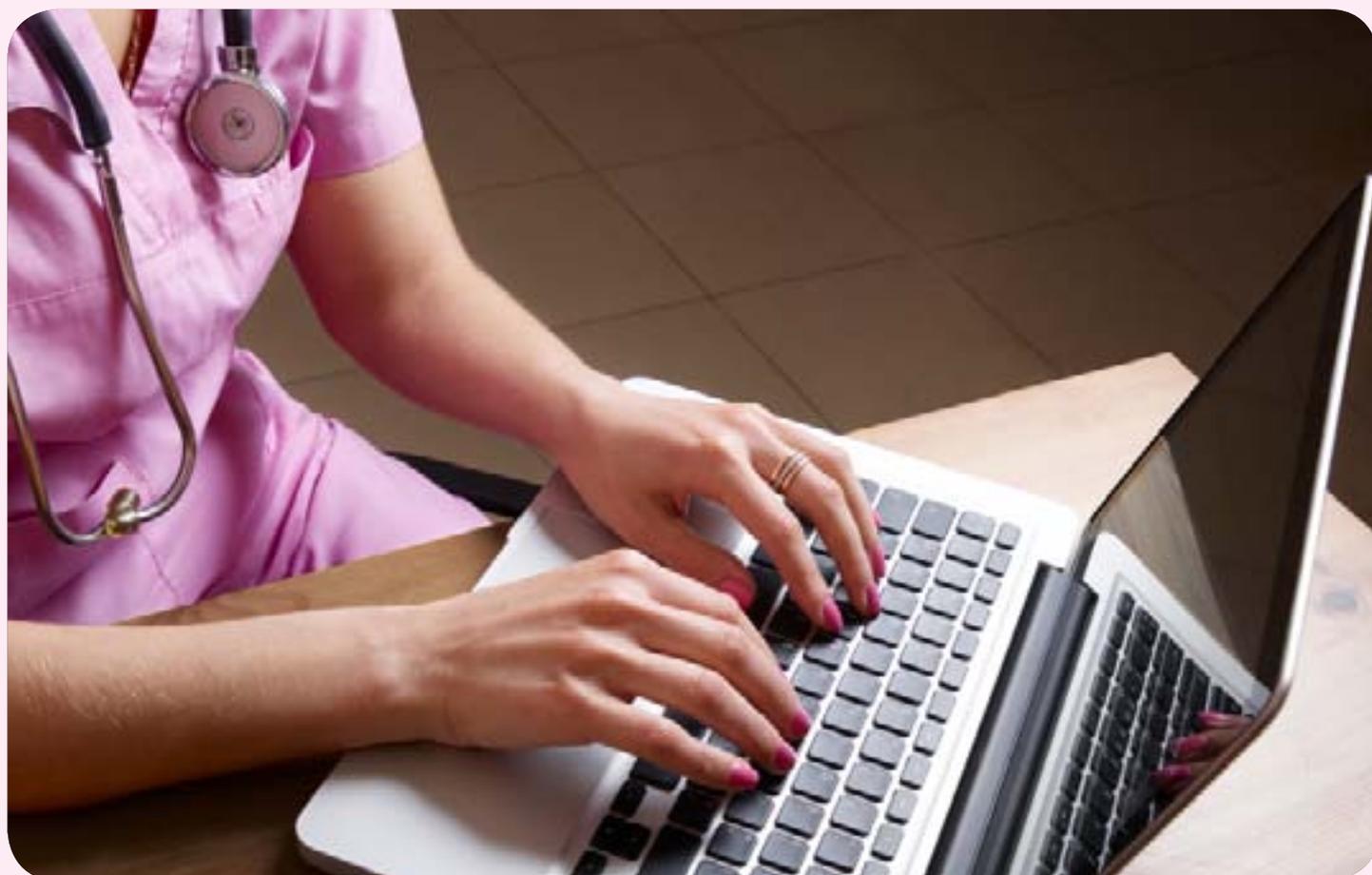
The resource will guide practice for health professionals through key practice points, and provide further referral options to specialist services, with web links to additional information.

Examples and tips on initiating the conversation will support health professionals to identify and prioritise a woman's key concerns and provide support to resolve these.

Access to resources and information are an important component in ensuring that women receive the best support after diagnosis, during treatment and on the road to recovery.

More information for those affected by breast cancer and health professionals can be found on the Cancer Australia website. The resource is due for publication later this year.

*Article submitted by Cancer Australia.  
[www.canceraustralia.gov.au/](http://www.canceraustralia.gov.au/)*



# What does the future hold?



**Women with cancer predisposition genes face complex decisions about future child-bearing decisions. Many women will need additional support in dealing with the complex and challenging information at the time of considering a genetic test and when they later want to have children.**

**President of the International Psycho-Oncology Society (IPOS), Professor Maggie Watson, examines the issues...**

In the mid 1990s major genes predisposing some people to breast and/or ovarian cancer were identified (BRCA1 and BRCA2).

This opened up the way for genetic testing to clarify risk of these cancers and support gene carriers in managing their risk.

Over the next decade genetic testing developed along with clinics where advice was offered on how to try to reduce this risk. This included increased access to breast and ovarian cancer screening as well as preventive surgery (mastectomy and oophorectomy).

Other options which potentially can reduce these cancers for future generations are pre-natal diagnosis (PND) and pre-implantation genetic diagnosis (PGD).

As a result individuals with cancer predisposition genes face complex decisions about future childbearing. What does PGD/PND involve? Why is it important? Who will benefit?

These are all questions of interest to

families where a cancer predisposition gene has been identified.

Both PGD and PND are technically possible to allow a mother to avoid having a child with a cancer pre-disposing change (mutation) in one of the BRCA genes where this has been identified in a family.

However both bring controversy and this has affected the pace at which these options have been rolled out. Specifically, PGD involves the selection of embryos or foetuses and PND would be done with the intention of terminating a pregnancy if the mother is carrying a child with the cancer gene mutation.

Both approaches raise a host of complex emotional, ethical, religious and cultural dilemmas.

PGD involves ovarian stimulation, egg retrieval and in-vitro creation of one or more embryos. From these embryos one or two cells are taken at a very early stage of development and tested for the familial cancer mutation. Embryos not carrying the cancer mutation can then be

implanted in the mother, in the hope that a pregnancy will be established.

The process is achieved through existing medical technology known as in-vitro fertilisation (IVF).

The second approach, pre-natal diagnosis (PND), involves the testing of a foetus early in pregnancy to see if it carries a cancer gene mutation. The purpose of PND would be to terminate the pregnancy if the foetus tests positive for a BRCA gene mutation.

An ethical dilemma would be created if a couple decide to keep a pregnancy in which a BRCA mutation has been found. If a mother gives birth to a child tested positive for a BRCA gene during pregnancy, that child is deprived of the individual's right in adulthood to decide whether or not they want to know their genetic status; a right that is considered to lie with the individual and not the parents.

In the United Kingdom access to PGD/PND is regulated by the Human Fertilisation and Embryology Authority

according to whether a particular condition satisfies requirements set out in the Human Fertilisation and Embryology Act (HFEA, 1990). In 2006 the HFEA extended licensing of PGD to include genetic susceptibility to breast and ovarian cancer gene mutations (HFEA, 2006).

There was some controversy at the time because BRCA genes, unlike some other genes for which PGD had already been practiced, involves a genetic disorder that would not cause cancer in everyone who carried that gene mutation.

Also, most BRCA mutation carriers are not likely to be affected, in terms of developing any cancer, until they reach adulthood. Furthermore, some preventive options exist that might help gene carriers avoid cancer.

Following careful ethical evaluation it was decided by HFEA that BRCA gene mutation carriers should be given the option of selecting embryos so that passing on the gene could be avoided. The options for termination of pregnancy on medical grounds already existed within UK law.

In this way the family risk could potentially and gradually be eliminated in the future. In 2009, for the first time in the UK, reproductive genetic testing was used to allow the birth of a baby girl who, through PGD, did not carry the same high risk BRCA1 mutation as her father.

So where does this leave young gene mutation carriers who have to make decisions about having children? This is a highly emotional topic. Also, what do gene mutation carriers know about these options?

To clarify these issues, our group at the UK Institute of Cancer Research began to ask some gene mutation carriers what they knew about these selection processes, what they thought about having children at high genetic risk of developing cancer and approaches for

selecting before birth, and what their needs might be for support in making decisions about having children.

As always in clinical genetics, the aim is to help and support people in their decision making. The research was aimed at finding out what would be helpful for those who are trying to make decisions about child-bearing so the genetic services could support them appropriately.

So what did we find out when we started to talk to women with a BRCA gene who were in the appropriate age group and might need to be aware of these issues?

Some talked about their right to life which would have been removed if their own mother had decided to avoid having them 'Just because you've got the gene doesn't mean you haven't got the right to a life' or 'you know that could've been me ... I could've been aborted'.

Others talked about modern medicine being able to help them avoid getting cancer; '... it's a gene that you can live with ... they're doing enough ... to prevent you getting it [cancer]'.

Still others talked about the difficulties of possibly terminating pregnancies just because of the BRCA mutation: 'I couldn't face the reality of having to abort that child ... there's nothing actually physically wrong with it at that time'.

For some women a clear distinction was made between selection of embryos through IVF and the termination of a viable foetus: 'If you're testing the embryos because they're not implanted you're not carrying it [the baby]' and it was not '... like I am actually pregnant'.

All those taking part in the research felt gene carriers should have the right to make their own decisions about childbearing and be given options. Pre-implantation genetic diagnosis was perceived to be a more morally and ethically acceptable alternative to prenatal

diagnosis by avoiding the need for a termination.

Although the moral and ethical implications of PGD/PND were mentioned by some of the women, these were considered to be of less importance compared to the benefits of potentially stopping the gene from being passed to future generations.

It's clear from what women said that more information needs to be made available to inform childbearing choices.

Many women had their BRCA test before they were thinking about starting a family, and then found it difficult to make these decisions knowing that they could pass on the BRCA mutation.

The family experience of cancer also played an important part in women's views; some had suffered a mother dying from cancer but others had seen their mother survive despite cancer.

The evidence showed that the desire for risk-reducing surgery also had an impact on family-planning; some women needed to consider removal of their ovaries.

There was also a sense that they were under pressure to have children at a younger age, so that appropriately timed risk-reducing measures can be taken in accordance with clinical recommendations.

Our study highlights that young people considering BRCA genetic testing need to be aware of the possible impact that a positive BRCA test result may have on their future decisions about having children.

Many will require additional support in dealing with this complex and challenging information both at the time of considering a genetic test and later when they want to have children.

*This article was submitted by Professor Maggie Watson, President of IPOS.*

## Questions women should ask:

- 1. How might my genetic test affect my choices about having children?**
- 2. If I want to have risk-reducing surgery to prevent cancer, how will this fit in with my desire to have children?**
- 3. What does PGD/IVF involve and how successful is it?**
- 4. Can my partner talk to the doctors and nurses involved?**
- 5. I want to talk about how this is going to affect me/us emotionally, is there someone I/we can talk to?**
- 6. My (my partner's) religious beliefs are important. What should I/we do and who can I/we talk to?**

# Peer support: Riding a new wave



Photo: Jill Kamicki

**Studies have shown cancer survivors report peer support to be beneficial. Peer support programs can provide a unique perspective and understanding from other survivors, which may differ from support received from family, friends and medical professionals.**

Despite the benefits, only a small minority of cancer survivors participate in traditional support groups (i.e. sitting in a room and talking about cancer).

The last decade or so has seen the emergence of peer support groups based on exercise or physical challenges for cancer survivors. Amazon Heart Thunder is one such event that provides a unique and inspiring peer support opportunity for women diagnosed with breast cancer.

Amazon Heart Thunder is based on breast cancer survivors riding Harley Davidson motorcycles and driving support vans for 10 days over 1,000 miles, with events taking place in Australia, the UK, and USA.

Anecdotal reports suggested that this event was a catalyst for positive life change and personal growth. Therefore, we conducted a research project investigating why this ride was such a transformative life experience for breast cancer survivors.

We invited participants from both the Australia and USA rides in 2009 to take part in surveys and interviews before and after the ride. Fifty-one participants took part in the study and were from a range of countries including Australia, United

States of America, United Kingdom, New Zealand, South Africa, Asia, Canada, and Europe.

On average, women taking part in this event were 50 years of age and had been diagnosed with breast cancer six years prior to the ride.

There were some women who had only recently been diagnosed and completed treatment, and some women reported metastatic disease.

**‘The knowledge that in some way we are wired in a similar way, when life got brutal, we got on a bike. That is enough for a lifelong connection.’**

The results of the surveys and interview data revealed a number of important factors occurring during the event:

- The safe network of other survivors provided understanding and acceptance, which encouraged self-reflection.
- Overcoming challenges during the event and the opportunity to bond with positive role models affirmed a strong survivor identity and promoted positive life changes.

- The positive influence of the facilitators, who were breast cancer survivors, provided encouragement and created a cohesive group dynamic.

- For some participants, a shift in identity was evident and they attached positive meaning to the term breast cancer survivor. For others the ride affirmed their sense of strength.

- Cancer-related distress significantly decreased after the ride.

This study highlighted that peer support events such as Amazon Heart Thunder provide an important alternative to traditional discussion-based support groups.

For these breast cancer survivors, this event was an opportunity to step outside of their day-to-day roles and take part in an activity that was about self-fulfillment and advocacy.

For some, this was the first time they were able to concentrate solely on themselves and not on family or others.

The sense of fun and freedom, group cohesion, and new social identity gained from being part of Amazon Heart Thunder was an affirming experience reminding women to embrace the warrior within.

*Article submitted by Bronwyn Morris, PhD, Research Fellow in Psycho-Oncology, Griffith Health Institute & Cancer Council Queensland.*

*b.morris@griffith.edu.au*

# RRI 2013: Mini-ride on the Garden Route



**In a joint effort to create awareness, Reach to Recovery International and Cancervive are planning a mass motorcycle ride from Port Elizabeth to Cape Town prior to the 17th RRI Breast Cancer Support Conference in South Africa. Register now!**

The route will take participants from Port Elizabeth in the Eastern Cape to the quaint village of Tsitsikamma for the first overnight stay.

The journey will continue through the beautiful Garden Route and Klein Karoo, covering the spectacular Outeniqua Pass and the Huisrivier Pass, staying overnight in Montagu in the heart of Route 62.

The last day will take participants through the beautiful winelands to finish in Cape Town.

'There is already a lot of interest from national and international survivors and we have had enquiries from as far afield as the USA and Australia,' Frieda Henning of Cancervive said.

Riders will be responsible for their own costs, which will amount to approximately ZAR 6 500.00.

This includes the entry fee (ZAR 1 500.00), motorcycle rental (ZAR 3 000.00), fuel (ZAR 600.00), plus accommodation and meals.

Sponsorships will be sought to cover some of the costs.

Cancervive will advise prospective participants on how to raise funds and obtain sponsorships, with participants allowed to display their sponsors' branding on their jackets and helmets.

Cancervive is a non-profit support group dedicated to awareness and education.

Email Cancervive to find out more!  
[www.cancervive.co.za/](http://www.cancervive.co.za/)

## RRI 2013 African Adventure

Pre and post-conference tours, as well as day tour options, are already available on the conference website and specialist tour operators have been engaged in order to assist delegates with planning an African adventure. The selected tours highlight the best of Cape Town and South Africa and will allow participants to truly connect with South African people, customs and life. We encourage you to bring your family along, make the most of what could be a once-in-a-lifetime trip to Africa, and take the time to see and experience some of the unique African experiences available!



**17th REACH TO RECOVERY INTERNATIONAL  
BREAST CANCER SUPPORT CONFERENCE  
20 – 22 MARCH 2013  
CAPE TOWN  
SOUTH AFRICA**

# Together We Reach for South Africa in 2013!

**Mark your diary to be in Cape Town, South Africa, for  
The 17th Reach to Recovery International Conference  
from March 20 to 22 in 2013.**

## **Together We Reach**

The 17th Reach to Recovery International Breast Cancer Support Conference will be held in Cape Town, Africa, for the first time from 20-22 March 2013. Enjoy stimulating conference sessions, with pre-conference workshops on March 19, a great social programme and the chance to visit Cape Town, South Africa.

The theme of the conference is 'Together We Reach' and we'll be looking at breast cancer from the perspectives of the patient (both the newly diagnosed and those with metastatic spread), the survivor, the partner, the family, the community, the breast cancer activist and the health professional. We will reach together to improve the quality of life for women and men with breast cancer.

## **Call for Abstracts**

Preparations are underway for Reach to Recovery International 2013 and this is your chance to help shape the programme.

We are looking for abstracts that will evolve into thought-provoking presentations and posters and are open to a wide range of proposals. All abstracts will be considered, but use the provisional programme as a guide.

## **Oral Presentations & Posters**

Oral presentations will be 20 minutes long with an additional 10 minutes for questions and answers at the end of the session.

Posters will be on display for the duration of the conference and presenters will be expected to attend their posters during breaks. Please take these logistics into consideration when preparing your abstract.

## **Registration Fees and Information**

Registration for the 17th RRI opened in August 2012, with discounts for early registration, African delegates and South African Reach For Recovery volunteers.

Click here to view the 17th RRI Registration Fees and Information or click here to be added to our mailing list in order to be notified when registration opens.

## **17th RRI is on Facebook and Twitter**

Join the Facebook and Twitter groups to keep up with conference developments and see which of your colleagues and acquaintances from around the world are planning to attend.

**Find out more about  
ABSTRACTS**

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**Visit the RRI website  
to find out more!**

# Sexual intimacy and survivorship: Asia in focus

**Across the globe, women are now living longer with breast cancer, and may be dealing with numerous intimacy, relationship, and sexuality issues, including those related to reproduction, especially so for younger women.**

Dr Loh Siew Yim from the University of Malaya Faculty of Medicine provides an Asian perspective on issues of intimacy and sexuality in survivorship.



**Sex plays an important role, beside its basic function for procreation, in enhancing interpersonal relationships, and building a more intimate, meaningful bond.**

Managing the medical tasks and the modifiable factors (like diet, weight, physical activity) are important but these should be complemented with patient self management of emotional tasks as well as role and relationships.

Issues of sex and sexuality are integral components of human functioning, participation and quality of life. It adds romance, enjoyment and enhances the quality of life of women.

Issue of functioning including sexual functioning should be relevant to Asian women, where breast cancer is more prevalent in 40-50 year olds compared to 50-60 in the developed countries.

However, in the traditional Asian clinics, sexuality is still neglected, and/or takes a back seat to cancer treatment and survival issues in people with cancer.

Even in the more developed Asian countries, like Japan, a study on breast cancer patients (n=102) found that discussing body image and sexuality were disregarded in therapeutic decision making situations.

Experiences of significant alterations in sexual functioning need to be addressed.

A research study in the USA found that sexual problems of women under 50 years (n=209) can be grouped into four main areas. These were a lack of interest in sexual activity, difficulty in becoming aroused, difficulty relaxing and enjoying sex, and difficulty achieving orgasm, with a lack of interest being the main challenge.

Nevertheless, these sexual issues are often not acknowledged in Asian

traditional medical model of health care delivery.

Many women are distressed by treatment-related sexual function or fertility-related adverse effects of treatment, but they are reticent to bring up the topic of sexuality given their lack of experience and low self-confidence, especially among younger Asian women.

In four focus groups conducted with Malaysian women living with breast cancer (n=39), a rising theme was on the neglect of sexuality issues.

In one of the groups, the women were quite open about their intimate relationships with their husband. This dispels the notion that Malaysian women in general are reluctant to talk about their private lives.

Although not a typical sharing in all groups, the author believes the use of focus groups have provided the impetus regarding the topic. These women's expressions negate the current belief that patients do not want to discuss sexual issues.

In our focus group, we found that sexuality and intimacy were two main role-related themes that emerged consistent as an unmet need across the groups.

In general, the women felt that their intimate relationships were affected to some extent, but they felt the main reason was 'within themselves' rather than with their spouse whom they reported as being 'encouragingly supportive'.

Some women sought clarifications and asked, 'Can we still have sex?' - as if sex after breast cancer will bring about detrimental consequences either on themselves or their spouse.

In fact, one spouse of the informant came forth with his query on the toxicity

of chemotherapy during sexual act of intimacy.

While some utterances from the women may seem to be exaggerated, this issue of sexual concerns does seem to weigh heavily on both the survivors and their spouse's minds.

Myths surrounding the issues of intimacy, chemotherapy and sexuality were not uncommon across the groups.

The excerpt below highlights some examples of common myths related to chemotherapy and cancer.

'My husband believed that with chemotherapy, I have the toxins all over my body, so it's better not to have it (sexual intercourse).'

'I heard that cancer patient cannot have too much sex because I heard that sexual excitement can lead to recurrence, and I want to know if it's true or not?'

These needs are critical but have been ignored in Asian's traditional medical model care delivery system. Sexual functioning, like other functioning, needs to be viewed as fundamental to health and quality of life.

Cancer is a debilitating illness. It robs years from lives and life from years because it traumatizes and detracts confidence, self-image, feelings of worth and pride, and the sense of normalcy from the survivors' daily functioning.

In addressing the unmet sexual needs of women and providing counselling about changes in sexual functions, as well as therapeutic tips to enhance sexuality, care providers must be aware that they are treating the patient as a whole and not just the cancer.

University of Malaya website -  
[//medicine.um.edu.my/](http://medicine.um.edu.my/)

Impact Through Translation: Cancer Research Informing Practice

**IPOS**  
INTERNATIONAL  
PSYCHO-ONCOLOGY  
SOCIETY



**Clinical  
Oncological  
Society of  
Australia**

JOINT MEETING OF  
**IPOS 14<sup>th</sup> World Congress and  
COSA's 39<sup>th</sup> Annual Scientific Meeting**

**BRISBANE, AUSTRALIA**

**11th - 12th November 2012 – IPOS Psychosocial Academy**

Full and half day workshops will be offered on a broad range of topics. Presented by prominent experts in their field these workshops are designed to provide participants with practical hands on learning and experience.

**13th - 15th November 2012 – IPOS 14th World Congress**

With a large number of world's leading psycho-oncologists, clinicians and researchers confirmed as invited speakers, the Congress program of plenary, symposia, oral abstracts and posters will ensure all delegates gain new understandings of the future opportunities for psycho-oncology on the international stage.

**Registration is now open**

**Early bird registration closes – 7 September**

For full details of the IPOS Psychosocial Academy and Congress Program please visit:

**[www.ipos-cosa.org](http://www.ipos-cosa.org)**

The 2012 IPOS 14th World Congress of Psycho-Oncology and Psychosocial Academy will be held in Brisbane, Australia's new world city, in conjunction with the Clinical Oncological Society of Australia (COSA) 39th Annual Scientific Meeting. The Congress and Academy are initiatives of the International Psycho-Oncology Society (IPOS), and will be hosted by Cancer Council Queensland, in partnership with the Psycho-Oncology Cooperative Research Group and the Australian Psychosocial Oncology Society.



# Faraja Cancer Support Trust, Kenya: Comfort, relief, rest

**Faraja Cancer Support Trust is a charitable foundation that provides emotional and psychological support to patients, carers and survivors of cancer.**

Faraja was established in 2010 to fill a void in Kenya and create an environment where patients could go to find emotional, practical and healing support together with a wide range of information.

Faraja offers cancer patients and their carers information, advice, counselling and complementary therapies in order to make their cancer journey a little more manageable.

In the past years over 1,000 patients have visited Faraja and used some of the facilities that it provides.

One of the fundamental keys to success is that it is run primarily by a group of volunteers who each offer a few hours a week in their areas of expertise. This can vary from admin, complementary therapies such as homeopathy, yoga, or simply a friendly face and a good ear.

These people come from so many walks

of life and their combined experience gives Faraja a special flavour.

This team is supported by a small number of permanent staff. Located at Cancer Care Kenya, Faraja is in the heart of the battle against cancer and a peaceful place for people to drop in and have a herbal tea and relax whilst waiting for treatment.

Research has proven that whilst medical intervention can be necessary it is looking at the patient's wellbeing as a whole such as their state of mind and nutritional wellbeing that has proved to be very beneficial in increasing the number of successes.

These therapies help to improve flexibility, immunity and determination all of which are essential in the fight against cancer.

Support group meetings have been another success story at Faraja. Starting off with only a handful of people at each session we now have up to 70 people coming for breast, prostate and cervical cancer meetings.

Led by professionals the aim of these meetings is to be patient centred to allow for the sharing of ideas and group healing.

These meetings guarantee a camaraderie of sorts, where patients understand each other and most importantly, identify with each other's problem.

At Faraja we have found that carers equally need support so they are welcome to come to meetings as well as join the patients in activities such as yoga.

Meaning 'comfort', 'relief' and 'rest' in Kiswahili, Faraja has come a long way in the past two years and will continue to strive to be the leading authority on cancer in not only Kenya, but East Africa.

The program has already been launched reaching out to 85,000 girls through 32 colleges and universities in Islamabad, Rawalpindi and Lahore. We have planned our next activations in Peshawar, Quetta and Karachi, and their adjoining cities.

For more details visit the Pink Ribbon Pakistan's website or Facebook page.

[www.pinkribbon.org.pk/](http://www.pinkribbon.org.pk/)  
[www.facebook.com/pinkribbonpk](http://www.facebook.com/pinkribbonpk)

## Anne Kimani Cancer Survivor

I am 23 years old and a breast cancer survivor. I was diagnosed with breast cancer early in 2010 while expecting my first-born Reagan, who is now five months old.

While going through surgery and chemotherapy, I was advised by my oncologist that I needed to go for radiotherapy. As soon as I began the 25-day treatment, I was introduced to Faraja. I visited the facility and was introduced to a variety of services they offered on a complimentary basis to cancer patients. I felt like the services catered to patients' emotions, which I found was a fresh approach.

So far I have managed to attend several movement and Reiki classes, and a nutrition session, with more therapies booked for before I finish my radiotherapy treatment. I have really benefitted from movement and nutrition programs, not forgetting group sessions where cancer survivors meet and share their experiences.

When I was diagnosed with



cancer I remembered a newspaper story from a few years ago about a young lady who was diagnosed when she was 19 years old, and I really wanted to meet her but I didn't know how. I was so fortunate that when I attended the group session, I found this lady who had also attended the same session.

Faraja Cancer Support has helped me realize that you have a future full of life. You experience relief from all the stress you get from talk of the illness.

You also get to learn more about the disease from a variety of resource materials available at Faraja for free!

## Syprain Kodiény Cancer Survivor

When I was diagnosed with breast cancer in September 2011, I was devastated, especially because my husband had recently been diagnosed with prostate cancer.

I went to many doctors and counselors in Mombasa only to receive poor feedback from them.

We finally met with a doctor from Aga Khan Hospital in Mombasa, the doctor recommended I begin with chemotherapy which I did in Mombasa and then she referred me to Cancer Care Kenya for radiotherapy.

I was told it's the best place to take the radiotherapy as they have the latest machines.

I was introduced to Faraja during my first week of treatment. The staff were very welcoming and explained the therapies and all the activities that take place such as movement, nutrition, stress relief and body talk.

I was glad to see the wide range of materials on the various cancers, and the library helped



me keep myself informed and to live positively as a breast cancer survivor.

The therapists have helped me to look at my life in a positive manner, have taught me a lot and they were responsive to all my queries and motivated me to keep fit.

Faraja should continue providing the love they have given me and also give it to all the people here.

My experience with Faraja has been very enlightening and beneficial and I would like it if they would start a similar center in Mombasa so that I can continue visiting them when I am back home.

# Global Kitchen

This edition, Global Kitchen brings you a recipe from Canada, the location of the UICC's 2012 World Congress!



Welcome to Global Kitchen, where we feature exotic recipes and home cooking from cultures around the world.

## Canadian Doughnuts

The Canadian Doughnut is a sweet pastry often enjoyed during winter months.

### Ingredients

- 8 tablespoons white sugar
- 1/2 cup warm water
- 1 tablespoon active dry yeast
- 1/4 cup vegetable oil
- 2 1/3 cups warm water
- 1 teaspoon salt
- 4 cups all-purpose flour
- 4 cups whole wheat flour
- 1 tablespoon lemon juice
- 1 teaspoon ground cinnamon



### Directions

1. Dissolve 1 tablespoon sugar and yeast in 1/2 cup warm water. Set aside until creamy.
2. In a large bowl, mix together oil, 2 + 1/3 cups water, salt, and 4 tablespoons sugar. Add yeast, and gradually mix in flour. Place dough in a buttered bowl, and turn to coat. Cover with a damp tea towel, and place in a warm place to rise for 1-1/2 hours.
3. Form dough into balls about the size of eggs, then roll flat to make ovals about 1/4 inch thick.
4. Heat oil to 350 degrees F (175 degrees C) in a deep fryer, pot, or electric frying pan. Fry doughnuts one at a time, until light brown on both sides. Place on paper towels to drain. Sprinkle with white sugar, cinnamon, and lemon juice while still hot.

*If you have a recipe to share, please email [info@reachtorecoveryinternational.org](mailto:info@reachtorecoveryinternational.org)*

# Nicaraguan breast cancer survivorship: Supporting each other in the fight



**More than 250 underserved Nicaraguan Breast Cancer survivors beneficiaries of the Fundacion Ortiz Gurdian Foundation (FOG) Cancer Program came together in 2005 and organized themselves as a group of survivors, initially with the objective simply to support each other.**

The group has now expanded its efforts to create awareness and hope in the fight against breast cancer.

The women credit their success to strong faith and the benefit of peer support, reaching out to other women to help improve survival in Nicaragua.

Martha Lorena Pavón, Isabel Paramo, Scarleth Balmaceda, Sonia Bravo, Alma Nidia Jarquin, Emilia Cuadra, to mention a few, continue their lives well and have become a group of promoters to educate women in rural areas, and to serve as a vehicle of reference, so that others receive free gynecological care in keeping with the prevention and early detection aims of the program.

This year more than 150 women affected by breast cancer travelled from across Nicaragua to attend a forum. The aim of the forum was to prepare an agenda for the work of the group, in order to formalize and give structure to their valuable volunteer work.

Survivors came from communities of Nueva Segovia, Estelí, San Miguelito, Matagalpa, Masaya, Jinotepe, Granada , Leon, Chinandega, and Jalapa .

**The survivors, as volunteers, have become a valuable vehicle of preventive health promotion**

It was unanimously agreed that each volunteer would strive in 2012 to connect with at least 10 women each (to reach a total of 1,500 women), to enlist them in awareness initiatives and provide access to information and educational pamphlets about breast health and examination.

To support this effort, FOG provides volunteers and survivors with training to carry the message and engage women in the early detection of breast cancer.

The survivors as volunteers have become a valuable vehicle of preventive health promotion - as living examples that the best chance to fight the disease is early

detection. Importantly, volunteers take fulfillment from knowing with certainty that through their work they are achieving a special purpose in helping other women.

They have organized themselves to make house calls - visiting door to door, neighborhoods, and communities near where they live, and carry the message. They each are responsible for bringing the women to the Ortiz Gurdian Breast Cancer Clinic for screening appointments and exams.

Their support entails accompanying the beneficiaries, and in the cases where any of them are diagnosed with breast cancer, they provide guidance and share their experience, emphasising the importance of keeping appointments for treatment, and most importantly, to not be afraid.

It is crucial for newly diagnosed women to hear from survivors, knowing that they have unconditional support from women who have experienced breast cancer.

FOG also provides financial support towards participation in physical therapy programs, such as painting and craftsmanship, as well as media training so that they can learn how to convey our message of hope.

*Article submitted by Teresa D. Campos, Coordinadora de Programas, Fundacion Ortiz Gurdian.*

# Mastectomy: Issues for low income countries

**The breast is one of the human body organs that constitute an important aspect of sexual enjoyment and intimacy.**

**For many women in low and middle income countries, community awareness and support is critical to overcoming the challenges of breast cancer and mastectomy.**



At the face of it, it appears like the sex act is merely an affair of the two people who are having sex.

On the contrary, the breast has a social role in a woman's life and the community at large.

The social perception of the breast and its importance varies from community to community and is time specific.

However, irrespective of the time and society, issues associated with the breast are very sensitive and one can dare say, almost universal.

And so a woman's disfigurement due to mastectomy will always elicit physical and social trauma.

This article focuses on this trauma in low income countries where resources committed to the health sector are much below the minimum recommended by WHO.

In such countries mastectomy spells social doom and death. This is understandable because breast cancer mortality rates can be high as 70 per cent within two to three years after treatment.

Much as these statistics are an indicator of poor health service delivery, a combination of social factors is another major contributor to this scenario.

For example, in some cultures a disfigured or disabled woman is more negatively perceived than a disfigured man. A woman with a breast disfigurement can be seen as a social outcast, a curse to the family and clan and sometimes a witch.

What man can marry such a woman!! However courageous, kind and understanding, social pressure will not spare him from submission.

Because of low levels of awareness about cancer in general, and breast cancer in particular, one of the beliefs is that breast cancer is contagious.

In such a situation even a loving male spouse might fear to touch the breast.

Such a fear is inevitably extended to the bedroom sex, which in turn creates rigidity, non enjoyment of the sex act and ultimately severance of the sexual relationship.

There are cultures where issues of child bearing are intimately linked with sex intimacy.

In such communities there are proverbs and sayings that a husband's love for the wife depends on the degree of enjoyment of the sexual act.

There is also the fear that mastectomy is synonymous with infertility.

Similarly in these communities where baby bottle feeding is unheard of, mastectomy implies reduced source of infant feeding which implies reduced chances of health babies and their survival compromised.

Again in cultures where sex is the epitome of a marital relationship and where the marital status bestows on woman recognition, respect, and a source of economic stability and security in old age, mastectomy is indeed social doom whose logical conclusion should be death.

These perceptions are a pointer at the kind and level of counseling that we who are engaged in breast cancer awareness raising and counseling need to bring out.

Issues of sexuality and intimacy and their social implications for survival have not had the attention they deserve.

For example one of the best breast cancer therapies at the male spouse level, is love, intimacy, caring and encouragement.

Spouse involvement through the cancer journey is very critical for healing and survival.

At the family and community level counselling and reaching out with psychosocial support is an additional therapy.

The male spouse needs this reach out service as well. This call is also being extended to medical practitioners engaged in treatment of breast cancer.

They have to be extra sensitive to the patient's trauma.

Remarks like 'I would have automatically removed that breast if I had done the surgery myself', or 'Don't worry, you will stuff that space (the breast scar area) with cotton wool and get on with life, come on', 'We have just saved you from a death trap, what's your problem' need to be avoided.

*Article submitted by Speciosa Kabwegyere  
Chairperson, Uganda Women's Cancer  
Support Organisation  
(UWOCASO)*

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## EVENTS

**BRISBANE, AUSTRALIA November 2012:**  
**IPOS 14th World Congress of Psycho-Oncology**  
**November 11 - 15, 2012**  
Go to [www.ipos-society.org/ipos2012/](http://www.ipos-society.org/ipos2012/)

**VIENNA, AUSTRIA October 2012:**  
**The Global Summit on International Breast Health**  
**October 3 - 5, 2012**  
Go to [www.bhgi.info](http://www.bhgi.info)

**CAPE TOWN, SOUTH AFRICA March 2013:**  
**The 17th RRI Breast Cancer Support Conference**  
**March 20 - 22, 2013**  
Go to [http://www.reachto\\_recovery2013.org](http://www.reachto_recovery2013.org)

## Our mission

Reach to Recovery International is built on a simple yet universal principle: a woman who has lived through breast cancer and gives of her time and experience to help another woman confronting the same experience is a valuable source of support. Reach to Recovery International is committed to working to improve the quality of life for women with breast cancer and their families through a wide range of services offered worldwide.

To contact RRI please email [info@reachto\\_recoveryinternational.org](mailto:info@reachto_recoveryinternational.org) or visit the website. The material published in Bloom does not necessarily express the views of RRI but is provided for the information of readers.

