

## Interview with Dr Madeleine Wall, 12 Sept. 2007

BCAC's Claire Ryan sat down with Dr Madeleine Wall, Clinical Leader of BreastScreen Aotearoa (BSA) and Jude Cooney, Communications and Marketing Advisor for the National Screening Unit to talk about mammograms and the breast screening programme for New Zealand women.



Dr Wall, Claire Ryan, Jude Cooney

*'Breast cancer is a multifactorial disease- there are very few factors that are amenable to manipulation and therefore, for the meantime, all we can do is ensure that women's cancers - when they do occur - are detected early and are treated well. That's what we concentrate on. I want to be able to provide a service that is acceptable to women.'* Dr Madeleine Wall

### About BreastScreen Aotearoa

BSA offers free screening mammograms to all New Zealand women aged 45-69 years with no symptoms of breast cancer. The programme aims to reduce deaths from breast cancer by detecting cancers when they are small. BSA organises screening services throughout New Zealand. Each BSA service is responsible for ensuring that eligible women in its region are given the chance to enrol in the programme. It must provide services of a high standard and refer women who are found to have cancer to treatment services. To contact any of these services, ring free phone 0800 270 200 to be automatically connected to the breast screening service nearest to where you are calling from.

### Dr Madeleine Wall

Dr Madeleine Wall (MB.ChB, FRANZCR) is the Clinical Leader of BreastScreen Aotearoa (BSA). Of Far North Te Rarawa and Te Aupouri, Dr Wall has worked within the National Screening Unit (NSU) since November 2002. The NSU is a separate unit of the Ministry of Health and is responsible for the safety, effectiveness and quality of health and disability screening programmes of which BSA is one.

### How did you come to be involved with BSA? What are the good things about BSA for you?

Prior to BSA, I worked with the Breast Cancer Screening Policy Advisory Group which gave advice to the Minister on how the programme should be set up. I then helped draft the initial quality standards (radiology sections) and helped set up the Wellington regional breast screen program where I was Clinical Director from 1999, until starting with the Ministry in 2002.

By international standards, BSA has excellent clinical results, with high cancer detection rates and good pickup of small, lymph node negative cancers, which, apart from the numbers of eligible women screened, are the most important elements to ensuring breast cancer deaths are reduced. The focus of BSA is on well women who are our initial clients, but we have a very integrated service to make sure that all women continue to be well cared for during diagnostic tests and up to treatment if that is necessary. This integration does not happen in all overseas screening programmes. In some countries, after an abnormal mammogram, women are faced with finding a service to do any follow up tests. Central coordination helps ensure that there is a similar level of service irrespective of where women live, and common standards, policies and protocols. This is possible partly because the NSU convenes groups of professionals and consumers who regularly review and improve standards and procedures and share lessons learned. There are many challenges, but the biggest of these is to increase the participation of women, particularly those who are at highest risk of dying of breast cancer - Māori and Pacific women.

**We often hear the message ‘Early detection is your best protection.’ Do you think there is some confusion over what this really means?**

The “protection” message is out there a lot. We hear some women say despite regular screening, BSA found they had a breast cancer - as if this were a failure of mammography screening. They think that because cervical screening prevents you from getting cervical cancer, the same is true of mammography and breast cancer. It’s important that women understand that if they are going to get breast cancer, they will get it whether they are screened or not, but if they screen, they are more likely to have successful treatment and so be more likely to keep their breast. The truth is mammography screening does not = prevention; it will not stop you getting breast cancer, but it can prevent you dying of it.

**How do you recruit women for the programme?**

No one single measure works so it has to be a mix of social marketing, for example ad campaigns to raise awareness. We also have initiatives to match GP databases with the BSA database. A GP - with a woman’s consent (most often the practice nurse will contact women and obtain this) - forwards her name to our provider who then confirms whether she has been screened or not and if not, we invite her. This allows the BSA providers to identify those women who have never been in before, provide them with information about the programme and to provide support into screening.

Educating and communicating with the GPs is very important to keep the databases up to date with address details especially when inviting women to come and be screened. BreastScreen South receives an updated list from GPs which they match up with theirs every quarter. They had 70% coverage for the total population but could not reach subgroups, particularly Māori and Pacific women, via GPs so they have put effort into making services more accessible for these groups, with great success. They are now over target and the first group we know of internationally to screen such a high percentage of a minority indigenous

population. It took a couple of years for BreastScreen South to win trust but they have turned a mainstream service into one that enabled these women to come in.

Some providers liaise with other groups at a local level, for example Asian women. Providers must know the needs of their communities but, on a national level, we must concentrate on the major disparities which are amongst our Māori and Pacific groups.

**A number of women in the community are concerned or afraid of having mammograms. What's the greatest concern or fear in your experience and what would be your response?**

Embarrassment, the fear of the mammogram process, the result and ensuing treatment are still there although these issues have lessened. Health promotion campaigns have been very effective. We commissioned a 3 year evaluation of health services, asking focus groups of women around the country 'what were the barriers to screening for you?' This information was used to develop a social marketing campaign and our first advertisements were based on some of this information. Some of the barriers expressed then are still relevant now - fear of the unknown, fear of the result and ensuing treatment are still key issues; but pain and discomfort and fear of the screening process are much less important this time. We are hearing women say, 'It was a positive experience for me' so there is more knowledge out there now. Research helps the National Screening Unit and local providers. For example, it is a mandatory requirement that women be offered a gown and also that all radiographers are women. At a local level, some of the barriers included inability to take time off work, accessibility issues and travel - so now the mobile unit is used and providers discuss with local communities the best place for the mobile to be in their town; some clinics offer evening screening appointments too.

**People also raise with us the view that "private is better." Without necessarily getting into the private v public screening debate, how stringent are the standards governing screening quality at BSA?**

The standards are the bible for providers. They cover the entire pathway, for example, timeliness, standards for how the mammogram is taken and minimum volumes. Our radiologists are required to maintain their expertise through breast specific continuing education and regular review of their performance statistics so they can learn how well they are doing and improve their practice. BSA monitors the providers very closely through external clinical and data audits. There is a continuous quality improvement programme with regular questionnaires for women and GPs. BSA has its own system to collect data from women as they go through the pathway so we can ensure they are receiving the quality of service we want them to have.

We do not give private providers accreditation unless they are working within BSA. Accreditation for BSA has stringent standards. Many BSA radiologists also work in private. 2 BSA accredited radiologists must read every mammogram and we give them their stats every 3 months which allows for continual improvement. If you never review your results you don't know how you're doing.

**Is it ok for women to bring whanau and friends with them when they come for a mammogram and does BSA take group bookings?**

Yes to both. Group bookings are often organised through health promotions but women can also ring 0800 270 200 to make them.

**How long does it take to get an appointment and does this vary in different locations?**

It varies according to the specific screening site in a particular region. The average time from enrolment to screening is 2 to 4 weeks. Where women have had mammograms outside of BSA, these must be obtained prior to the screening appointment, which may extend a woman's waiting time. Also, if women are waiting until the mobile makes its annual or 2 yearly visits nearby, waiting times can be much longer. If location is not a priority, there will be a site women can travel to within their region where they only need to wait a few weeks. BSA does not provide an acute or emergency service. We provide a regular, routine service. Our priority is to ensure that once women receive their first mammogram with us, they are screened again 24 months later. We monitor this statistic very closely i.e. what % of women are re-screened within 24 months. It is a concern if women drop off. Each provider must have 'fail safes' so they do not lose anyone's name. We are concerned that the length of waiting time may impact on a woman's willingness to come in. If she has to wait 6 months, she may have changed her mind so we must ensure that our service is accessible but also timely.

**The personal stories on your website are inspirational and reach out to Māori in particular. How do you obtain volunteers for the stories?**

The local health promoters and screening services ask their clients, who have been generous in giving us their time and stories for the benefit of other women.

**Would you consider having Pacific, Pakeha and Asian stories on your site as well?**

Yes. Currently we are targeting Māori and Pacific women both nationally and at a local level, because these groups are at a higher risk of dying of breast cancer than others and therefore would potentially benefit the most from screening. Our priority is to eliminate that disparity in survival. Asian women immigrants have a lower incidence of breast cancer and also have a reduced risk of dying of it than others, but local BSA initiatives do occur where there are under-screened immigrant populations.

**We are often asked how women who have had breast cancer rejoin the programme or enrol for the first time - what's the answer? Would you recommend an annual mammogram for such women?**

5 years after your treatment: Ring 0800 270 200 to enrol or log on to [www.breastscreen.org.nz](http://www.breastscreen.org.nz) and enrol online. It is preferable for women to continue to have follow-up through their GPs or treating surgeon or oncologist.

In line with some international guidelines, we currently advise women to have annual mammograms following a breast cancer diagnosis. These guidelines also recommend that women should have that performed in a clinic or by a GP where they will also get a clinical examination and review of any ongoing cancer treatment they are receiving (e.g. Tamoxifen or aromatase inhibitors). BSA does not provide routine clinical examination or treatment review and therefore it is preferable that breast cancer survivors receive that through DHB provided services.

DHBs are funded to provide annual mammography for women who are at high risk of developing breast cancer because they have any one of the following:

- ◆ a mother or sister with pre-menopausal breast cancer or bi-lateral breast cancer,
- ◆ had a previous breast cancer
- ◆ a breast histology demonstrating an at risk lesion (for example, atypical hyperplasia)

These mammograms are provided outside of BreastScreen Aotearoa either at the local hospital radiology department or at DHB contracted private radiology services. A GP referral is required unless a hospital surgeon or oncologist is seeing you.

You express your concerns in the BSA publication in March 2007 ([http://www.nsu.govt.nz/Files/Women\\_breast\\_cancer\\_symptoms2.pdf](http://www.nsu.govt.nz/Files/Women_breast_cancer_symptoms2.pdf)) that symptomatic women may self-refer or be referred by their GPs to BSA and this may delay a diagnosis of breast cancer. Is this delay because of delays in waiting times? Not really. The delay is because she gets into the wrong pathway and then needs to be sent back to ensure that any symptomatic cancer that does not show on a screening mammogram is detected and treated.

**If there were little or no delay, would this continue to be a problem?**

Yes. Symptomatic cancers may not show up on a screening mammogram. So, the appropriate first test for a woman with breast symptoms is a clinical examination. Where there are persistent signs or symptoms, referral for imaging (e.g. diagnostic mammography and ultrasound) targeting the area of concern, and often a needle biopsy, follow. These women already have a problem that needs a diagnosis, which is why the clinical examination is so important.

Because BSA is set up to cater for women who do *not* have symptoms, the first and only test for the vast majority (95.5%) is a screening mammogram. The BSA mobile services allow easy access for those who would not be able to have screening mammograms because they live or work far from a hospital or radiology practice. The trade off is that this service is only available in any one site for a few weeks in a 2-year period, so women living in that area wait for their first BSA mammogram until the mobile arrives for its next visit. It is only if there is a problem that shows on the mammogram that a woman is then required to travel to a central site to have further investigations.

**How often are women with symptoms self-referring or being referred to BSA?**

It varies around the country, but in most areas, inappropriate referral appears to have reduced since the programme started. This is because of ongoing education of women and GPs by regional BSA providers about the 2 publicly funded pathways - BSA for women without symptoms, DHB diagnostic services for women with symptoms and high risk women.

**Is the policy that they are turned away and told to see their GP?**

At enrolment women are advised to see their GP promptly if they have a symptom, and to come back once they have had that investigated.

**Does BSA refer such women to a GP?**

If a woman with symptoms is screened and the mammogram is normal, she is referred back to her GP to have the symptom investigated with a clinical examination initially. This may mean that she then needs a referral to have diagnostic tests through the DHB.

**What of women who are concerned about the cost of seeing a GP?**

For some, the cost of seeing a GP is prohibitive and this is what the primary health care strategy is trying to address - to ensure that those who need to see their GP for any reason can do so irrespective of their economic circumstances. There is evidence that the strategy is beginning to work, with greater numbers of lower income people seeing GPs around the country.

**Is the message you wish to convey strongly that women with symptoms should be promptly referred to a DHB diagnostic service?**

Women with symptoms need to have their GP investigate that first. If necessary, they should then be referred to a DHB diagnostic service for further tests. Not all symptomatic women will need to go on to a clinic.

**How are you conveying that message to GPs?**

Over the years, GPs have been sent information packs and articles written for GP journals and magazines. We also convey the message via BSA regional GP coordinators, radiologists and surgeons, and I speak at GP update courses. Most recently, this issue has been addressed through an article in the NSU's screening newsletter which goes to every GP in the country.

**It is well known that the national screening target is 70%. The national rate as at the end of 2006 was 35.8% for women between 45 and 49 years and 61.5% for women aged between 50 and 69 years. For Māori women, the total of eligible 50-69 year old women screened was only 40.9% and for Pacific**

women, the total was 40.8%. BreastScreen South leads the country with 67.9 % in the 45-49 year bracket, 79.3% in the 50-69, 66.5% of 50-69 Māori women and 68.4% Pacific Island women. What's its secret?

1. Involvement of GPs to identify those who have not been screened. These women can then receive personal invitations, information and support, as necessary, to make an informed decision about whether they want to have a screening mammogram within BSA.

2. Coordinated activities between the screening providers (particularly appointment staff) and local health promoters has made the difference between initial 40% screening rates for Māori and Pacific women in BreastScreen South and the current rates of over 70% for women 50 - 64.

**How does BSA propose to increase its screening of eligible women? In particular, of Māori and Pacific women?**

The NSU is working to roll out the successes of the BreastScreen South initiatives to other areas, and some regional BSA providers and PHO/GP groups are making progress towards that. There is a comprehensive strategy involving: 1. regional social marketing campaigns to raise awareness of the programme; 2. work with the primary health sector through DHBNZ and regional providers to identify and invite women; and 3. locally devised health promotion initiatives to meet the specific needs of local communities.

**How do you see groups like BCAC assisting NSU in achieving its screening targets?**

Many of the BCAC member groups comprise knowledgeable women who have been through the process. They know the limitations and advantages of screening mammography, and also know that it offers the best hope of early detection and subsequent survival. Their willingness to share their stories does more to help other women overcome the fear of the unknown and have that first mammogram than any amount of literature and statistics that I can provide. So, continue to do what you already do - share the many different stories you have with other women.

**Finally, what is your message to whanau and family in this country?**

There is little that women can do to prevent getting breast cancer, but early detection with good quality screening mammography and treatment offers women their best chance of surviving the disease. For many women, breast cancer can be beaten.