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*Penny Webb*  
(Courtesy Qweekend)

Welcome to the 3rd OPAL Newsletter. It is now about 2 years since we started the OPAL Study and, thanks to all of you who have agreed to take part, we now have just over 700 participants and have collected more than 3000 questionnaires and 700 blood samples. Although we can't really start analysing all the information you have provided until after we finish recruitment at the end of this year, we have included a few 'snap shots' on page 3 to show you the sorts of things that we are looking at. As you know, our original plan was to ask you to complete questionnaires for up to 2 years. We have, however, been fortunate to secure some additional funding (see page 2) so, as the study is going so well, we are hoping to be able to continue for an extra year. This will mean that instead of saying goodbye after the 24 month questionnaire, we will ask if you are happy to stay in the study for an extra year. If you agree, we would continue to call you every three months to find out how you are going and would send you a final questionnaire at 36 months. You are of course under no obligation to continue, but we would be very grateful if you did.

**Penny Webb, Principal Investigator of OPAL**

## Getting to know our newest OPAL team members

**Rebekah Cicero** and **Sharan Burton** are the newest members of the OPAL team. Many of you will have had a call from them and if you haven't spoken to them yet, you will at some time.

Both Rebekah and Sharan were working on other studies here before they joined the OPAL Team. Rebekah is busy on the phones calling you to collect data for the 'MOST' questionnaire. Sharan is managing the 24 month questionnaire as well as collecting information from OPAL women who are recruited through Monash Medical Centre in Melbourne and the Hunter region in NSW.



*Sharan Burton and Rebekah Cicero*



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# Thank you to our fundraising heroes



*Penny Webb and Barb Mackenzie*

**The Brisbane Women's Club Charitable Trust** for donating the very generous sum of \$10,000. These funds have allowed us to extract DNA from the first 500 blood samples we have collected from OPAL participants so we can take part in a major international collaborative study. This study aims to increase our understanding of how a woman's genetic background influences her risk of developing and surviving ovarian cancer. Penny Webb and Sue O'Brien recently attended the BWC Annual Morning Tea to thank them for their very generous grant.



*Helen McCloud with the OPAL bucket at Hartwood music festival*

**The Cory Family Charitable Foundation** for donating \$9200 to allow the OPAL study nurses to attend the International Gynaecologic Cancer Society meeting in Melbourne in November. This is the best meeting of its type in the world and it is very exciting that it will be held in Australia this year. Research funding rarely stretches to allow us to attend meetings such as this so we are all very grateful to have this opportunity to bring the OPAL team together for a training workshop and to extend our knowledge of gynaecological cancers.

**The Hartwood Music Festival** and its wonderful organiser, **Helen McCloud**. Helen is an OPAL participant and has been running this festival in country NSW for the past 27 years. This year she passed around an OPAL bucket and raised \$2000 for our study.

## Medicare



We would like to thank everyone who has already provided consent for us to access their **Medicare records**. We are asking you to do this to help us find out whether some medicines may help prevent ovarian cancer from recurring.

For those of you who have recently joined OPAL or who have not yet had a chance to reply, we have enclosed a letter explaining the Medicare consent. If you are happy for us to access your Medicare information we would be grateful if you could complete the consent form and send it back to us in the reply-paid envelope provided.

If you do not wish to consent to this aspect of the study please tick the box on the letter and return it in the reply-paid envelope.

# OPAL gets funding from BUPA and the Weekend Walk to End Women's Cancers

**Professor Michael Friedlander**, one of the OPAL Study investigators, was fortunate to be awarded a grant from the **BUPA Health Foundation** to help fund the collection and analysis of data from the 'MOST' questionnaire that we ask you to answer every 3 months. We hope to show that this provides a more reliable way to detect ongoing side-effects and symptoms and that it will lead to better patient care in the future.



Professor Friedlander

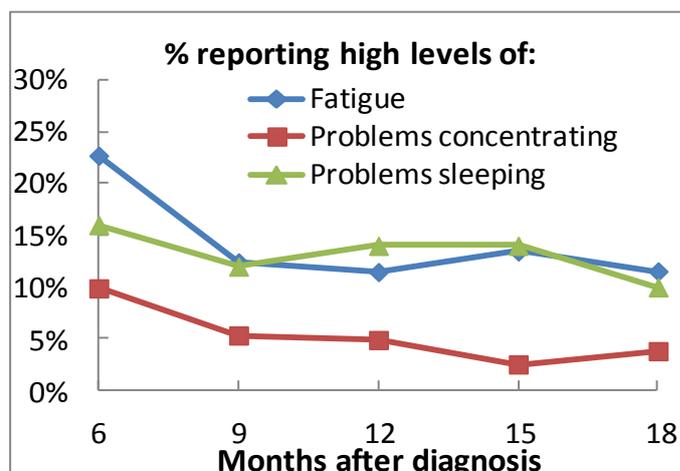
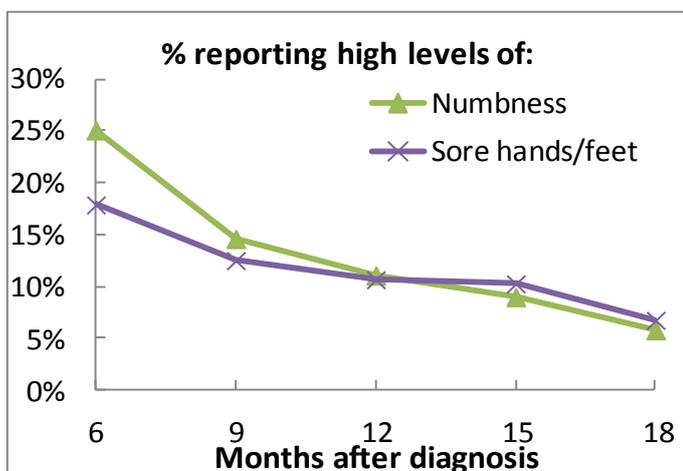
In our last newsletter we mentioned that several OPAL Team members walked 60 km over two days to raise money for women's cancer as part of the '**Weekend Walk to End Women's Cancers**'. We are very pleased to tell you that the OPAL Study was awarded \$28,000 from this to help fund collection of data from the 'MOST' Questionnaire. See below for some early data from this part of the study.

## Some early data from the 'MOST' Questionnaire

We have started looking at some of the answers you have given on the 'MOST' questionnaire. The first graph below shows that while about 1 in 4 women report high levels of numbness and/or sore hands or feet when they finish treatment, for most women this improves over time. The second graph shows that many of you also report problems with fatigue and concentrating but again these things often improve over time. In contrast, problems with sleeping appear to be a bit more persistent.



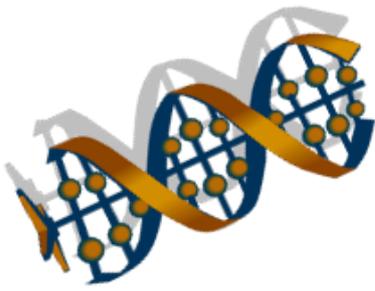
The Walk to End Women's Cancers



## If you are finding it hard to cope....

A diagnosis of cancer can impact on all aspects of life and this may affect you emotionally as well as physically. If you are finding it hard to cope emotionally we recommend that you talk to someone about this. The best person to talk to would be your treating doctor or GP, but if you do not want to talk to them you could contact your nearest **Women's Health Centre** or **Community Health Centre** or ring the **Cancer Council Helpline** on 13 11 20 (local call) between 9 am and 5 pm, Monday to Friday. The Cancer Council also provides online support through their **Cancer Connections** website (<http://www.cancerconnections.com.au/>), where you can ask questions and take part in groups, forums and blogs.

**If you feel distressed now and want to talk to someone, you can ring Lifeline on 131 114 (local call).**



## Genetic testing...important information

Several of you have called or emailed to ask if we have tested your blood samples for genetic mutations, especially in the *BRCA* genes and, if so, whether we can give you the results. The answer is that we have not yet done any genetic testing as it is better for us to test all of the samples at the same time. As we mentioned, your samples will be tested towards the end of this year to look for evidence that other genes play a role in ovarian cancer risk or outcome. However this testing will not include the *BRCA* genes. Unfortunately, although we can get some testing done cheaply, tests for *BRCA1* and *BRCA2* are still very expensive even for us so we cannot routinely test for them. Another complication is that, because of the possible implications of a positive *BRCA* test result to women and their families, women who want to be tested have to have genetic counselling and any 'research' testing we do would also have to be confirmed in an accredited laboratory. In short, if we did find something important we would have to first ask if you wanted the information and then refer you to a Genetics Service for counselling and repeat testing anyway. It is all very complicated!

So, we do have samples of DNA from some of you that could potentially be used for *BRCA* testing but we cannot provide you with any results at this point in time. There have however, been changes to the guidelines for genetic testing and it is our understanding that (in some states at least) it is now recommended for all women with certain types of ovarian cancer (serous cancers) if they are aged less than 70. If you want more information about this we suggest that you talk to your doctors or your GP.

## Why haven't you asked about.....

We often get asked why we haven't asked about other things that you think are important. The short answer is that we could not ask about everything that we were interested in because the questionnaire would have been far too long. It is also very hard for us to make changes to questionnaires part way through a study. We do however, always include a section where you can tell us about extra things that are important to you. So, if you think we are missing something please do tell us about it and we will look at this extra information.

## LIVING WITH CANCER, our research your future

**Penny Webb** has been invited to present at this interactive forum hosted by Ovarian Cancer Australia and the Prostate Cancer Foundation of Australia (PCFA) in Brisbane later this month. Penny will be discussing survival issues and the OPAL study. A full report will follow in the next newsletter.

