

OPAL Newsletter

Issue 7 Summer 2017

Welcome to the seventh issue of OPAL News. As always, the OPAL team has been very busy over the last 12 months with 480 new OPAL questionnaires and 1788 MOST questionnaires to be entered into our databases. We were also very fortunate to be awarded another grant from the National Health & Medical Research Council of Australia which will allow us to continue collecting and then analysing the OPAL data. Our first main analysis is looking at whether lifestyle can affect the side-effects that women experience during treatment (see below). We have also been talking to some of you about your personal experiences of chemotherapy (the COPE Study) and have included some early results from this study.

The OPAL study has been running for nearly five years now so we are saying goodbye to increasing numbers of you who joined the study early on. To everyone who has reached the 4-year point, and we have now received 121 final questionnaires, we are hugely grateful for your contribution to the study and will miss talking to you. We wish you all the best moving forwards and hope to keep in touch via these newsletters. Please let us know if you no longer want to receive them. To those who have not yet reached this milestone, we are very grateful for your ongoing commitment. We know our questionnaires may sometimes come at a difficult time for you or may be an unwelcome reminder of what you have been through so if this is the case then please talk to us. I would also like to stress that we don't just want to know about the good things – in order to know what really matters and where we might be able to make a difference we also need to know about the bad things.

As always, if you have any questions please feel free to call one of our team on our freecall number 1800 222 600 or email us at opalstudy@qimrberghofer.edu.au.

Best wishes,

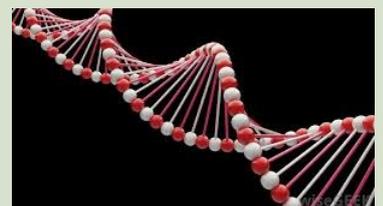


Lifestyle and chemotherapy side-effects

Almost everyone experiences some side-effects during chemotherapy but we have found that three quarters of the women in OPAL had side-effects that were judged to be moderate or severe and, as a result, two thirds of women needed changes to their treatment. We are now looking at whether we can predict who is most likely to experience severe side-effects so that these can be managed better, and also to see if there are any aspects of lifestyle that make it less likely that a woman will need to delay or change her treatment because of severe side-effects. We will keep you updated with the results of this work.

The OncoArray Study

As you know from previous newsletters, we sent about 500 OPAL samples to be part of a large international study looking for new genes that might predict a woman's risk of developing ovarian cancer. This project involved more than 50,000 women worldwide. The first results will be published later this year but the main outcome is that the study has identified 12 new genetic markers that appear to be associated with a small increased risk of ovarian cancer. Unlike *BRCA* mutations which are rare but greatly increase a woman's risk of getting ovarian cancer, these new markers are very common and have only a very small effect on cancer risk. Unfortunately, this means that we cannot use them to identify individual women who are most at risk of ovarian cancer but, if we can identify what the new genes do and why they are important, we may be able to develop new treatments. If you have asked to get feedback and we do find out anything that might be relevant to you, we will contact you about this.



Note: if you said that you did not want your samples to be used for genetic research or to be given to other scientists for approved studies they were not included in this study.

“COPE” The Chemotherapy Outcomes and Personal Experience Study

As part of OPAL we have asked you questions about things we think might be important to women with ovarian cancer. Between November 2016 and January 2017, we turned this around and spoke to 18 OPAL participants in detail to find out what *they* thought had helped them cope during their chemotherapy. Drs Vanessa Beesley and Aleksandra Staneva (pictured right) are very grateful to the women who agreed to talk to them and felt very privileged to hear their personal stories. Although they are still working on the final analysis, what we know for sure is that each woman had a unique story. Some found their treatment very challenging and exhausting and said the social, emotional and practical support they got from their partner and close family was most important in helping them deal with the side effects. Others believed in ‘following medical advice to the letter’ and said the most important thing for them was to have open communication with their doctor. All women shared a fond appreciation for the staff and nurses, and their genuine care. Apart from keeping busy and trying to stay positive, finding ways to nourish the soul during the difficult times was essential. A rather unique way of emotional coping and healing for one of our participants, was writing a book of poems. With her permission we share a poem (right) which she wrote while undergoing chemotherapy.

Vanessa will present the results from this study at the 13th Behavioural Research in Cancer Control Conference



Lynparza is now listed on the PBS

Some of you may like to know that Lynparza (also known as Olaparib) was listed on the PBS in February 2017. This is a significant milestone for women with high grade serous ovarian, fallopian tube or peritoneal cancer who also have a *BRCA* mutation in their genes.

Lynparza is a type of biological therapy called a PARP Inhibitor. It is an oral prescription drug for women who experience a recurrence of their cancer and have at least a partial response to a platinum containing chemotherapy drug.

There are certain criteria that women will need to meet in order to qualify for this new drug. If you think you may qualify or if you would like more information about this drug, you will need to visit your oncologist. They will know if this is an option for you and will be able to provide you with the necessary information.

Today is nine October
Two thousand and fifteen
I try so hard to still the nerves
Clear my mind and be serene
I close my eyes and slow my breath
And find my inner calm
I see a four leaf clover
A magical good luck charm
And then I see the lotus
A flower so beautiful to all
And the answer that it's given me
Is to rise above and stand tall
Then a vision of a diamond
A spiritual crystal of light
A symbol of strength and courage
That will protect me day and night
And finally a phoenix
A mystical magical vision
And that same day my doctor tells me
Sheree, "you are in remission"

From Sheree's Little Book of Healing