

# Australian women finding answers

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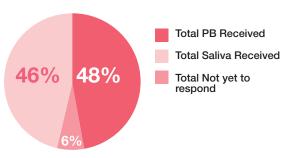
# **An Update About Lifepool**

If this is the first time you have received a lifepool update, welcome! The newsletter is designed to keep everyone informed about progress in developing lifepool and about the research using information provided by you, the participants. We hope you find the newsletter of interest and invite you to contact lifepool with any feedback you care to provide.

Donation of DNA Form' and would like to donate, it's not too late. We are happy to receive your sample whenever it is convenient for you.

There is an update about a research project which has applied to use DNA from lifepool participants below.

#### Overall DNA Donation



100,000 50,000 23,488

To date we have over 23,000 participants!!

#### **Recruitment Update**

Recruitment of women into the lifepool Project has been outstanding! To date we have over 23,000 participants!! The majority of women joining lifepool have been invited via Breast Screen Victoria and now we are pleased to say that women can also learn about lifepool as part of Register4. Register4 is an online community set up by National Breast Cancer Foundation. People interested in supporting breast cancer research join Register4 and are sent information about research projects. Lifepool was offered to Register4 Victorian members at the beginning of August. If you are interested in learning more about Register4, go to www.register4.com.au.

We have also created the lifepool facebook page. The more people who 'like' it, the faster we can spread the word about lifepool. Check out www.facebook.org/lifepoolProject for more information.

We are continuing to write to Lifepool participants with a request for a DNA sample, provided in either a blood or saliva sample. The response has been terrific. So far we have over 1000 DNA samples ready to be used for approved research. If you who have received a Stage 2 'Participant Information and Consent:

# **Hearing From You**

Lifepool recently asked the Social Research Centre to conduct a survey of lifepool participants. We wanted to understand what women thought of the recruitment process and to learn if there were things we could improve. A group of 25 women were interviewed at length by Alana from Social Research Centre. The research findings show that all participants generally felt highly positive about the experience of taking part in the lifepool Project. Our information was clear and understandable. We learned there are some things we can do better and have taken on board your comments about acknowledging receipt of your documents quickly. We are working on an email message which will go out to the approximately 500 to 1,000 women registering with lifepool per week.

Thank you to all the lifepool participants who considered our request and a special thank you to the women who generously gave their time to be interviewed.

# Research Using The Lifepool Resource

Validation of breast cancer susceptibility genes:
 Assoc Prof Ian Campbell & Dr Ella Thompson

Cancer occurs when individual genes within the body's own cells become mutated and stop working normally. To develop better ways of detecting and treating breast cancer we need to understand more about these faulty genes. The task of finding one faulty gene among the approximately 22,000 genes in each cell of the body is difficult.

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Our major focus has been to understand why breast and other cancers occur very frequently in some families. We know about some of the genes that cause breast cancer in families, such as BRCA1 and BRCA2, but these genes only explain about 1 in 5 breast cancer families. We believe there are many other genes that remain to be discovered that cause breast cancer in families. Our aim has been to use new gene sequencing technologies to identify these genes.

Over the last 3 years we have been perfecting the technology that allows us to screen all 22,000 genes in each cell of the body to find the one change that can cause an increase in cancer among families. To date we have analysed the DNA from 130 women from 64 high-risk breast cancer families and have already identified the faulty gene in 9 of these families.

Unlike previously discovered genes such as BRCA1 and BRCA2, it seems the remaining genes will each account for a very small number of families. As a result it will be much more difficult to prove that a new gene is genuinely involved in cancer

The only way to prove a gene is involved in breast cancer is to screen very large numbers of women to demonstrate that mutations in the new gene are only found in women with breast cancer (or a family history of breast cancer) but not in women without cancer.

Finding large numbers of women without breast cancer to screen has been difficult in the past, which is why Lifepool is so important. The DNA samples donated by lifepool participants are assisting us in identifying new breast cancer genes and speeding up the process of translating our findings into the clinic

 The impact of digital mammography on the measurement of mammographic density.
 Dr Jennifer Stone & Prof John Hopper

Mammographic density (the relative proportion of white versus black areas on a mammogram) is a strong predictor of breast cancer risk. Mammographic density cannot be determined by feel or touch but can be measured in anyone willing to undergo mammography.

Everything we know about mammographic density has been gleaned from measurements taken from film mammography.

Around the world, there are many different types of mammogram machines, both digital and film based. The majority of BreastScreen Victoria services have made the transition to digital mammography. Each digital mammogram machine 'brand' processes images in a slightly different way.

We have developed new automated software that could be used by breast screening services to measure mammographic density at the time of a mammogram.

This software needs to be tested on all types of mammograms to ensure it can accurately measure mammographic density, and can then be used to identify women at increased risk. This could lead to earlier diagnosis and therefore, better breast cancer outcomes. Our research will request digital mammograms from lifepool women who have previously undergone film mammography at BreastScreen.

We will calibrate mammographic density measurements between film and digital mammograms so that direct comparisons can be made. We will also compare the associations between mammographic density and breast cancer risk using measurements from different types of mammograms - film, raw digital and processed digital mammograms as matched 'sets' from the same group of women. It is vital to have this data available from a large group of women who do not have a breast cancer diagnosis. We can then compare these images with mammogram images from women who have been diagnosed by BreastScreen Victoria to test how well the automated software can predict risk.

We will continue to communicate via our lifepool News, but please don't hestitate to contact us at any time if you have questions about the project.

Don't forget to spread the word to interested family and friends.

### Thank you for your support

#### The **life**pool Team

Ian Campbell, Stephen Fox, John Hopper, Anne Kavanagh, Bruce Mann, Gillian Mitchell, Vicki Pridmore.



## Contact lifepool:

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