#### Study Update

2,800 women have joined DietCompLyf since 2004

**3,390 women** have joined the study since 1998

56 collaborating NHS hospitals nationwide are involved in the study

Almost 22,000 blood & urine samples have been collected for analysis

All participants have reached at least their year 3 visit

## How we protect your data

We want to assure you that we adhere to the highest standards in the safekeeping and use of your data.

Only authorised study personnel are granted access to your personal information.

All files are stored in locked cupboards, located in a secured room.

All patients are identified solely by their unique study number and initials when data is handled.

All the data we receive is transferred onto a protected computer drive that only study staff have access to.



# Study Newsletter

Issue 5, 2013

Welcome to the fifth annual issue of the DietCompLyf study newsletter.

Thank you for taking part in our study again this year and helping us to investigate the effects of diet, lifestyle habits on breast cancer. DietCompLyf is the largest study of its kind within the UK and among the largest in the world. We are delighted to have reached this stage and we are grateful for your contribution.

#### Quality of Life

Quality of life is a term used to describe how an individual perceives their own general well-being and health status: it can be affected by a number of factors. We understand that quality of life is extremely important and we are looking at ways that quality of life can be improved for everyone, and particularly for those recovering from breast cancer.

The lifestyle questionnaire that was completed at recruitment for the DietCompLyf study incorporated an assessment to evaluate quality of life. The European Organisation for Research and Treatment of Cancer (EORTC) designed the questionnaire that was used and validated it to ensure the questionnaire measures what it was designed to. Many other cancer studies have also



used this questionnaire so we can compare our results to other research and increase our understanding this area. The questionnaire allows us to monitor the participants' physical. social. psychological, and emotional wellbeing, symptoms and overall quality of life.

There has been an excellent return rate of the questionnaires: we received 95% of the questionnaires that were given out at recruitment. We hugely appreciate this response and it has given us a lot of data which we are investigating this includes many aspects of diet and lifestyle including quality of life.

The General Health Questionnaires that are completed annually at every study visit are used to evaluate general well-being and anxiety. We can correlate the quality of life scores with the general health scores and track these over time during the course of the study. We will then look to see if any dietary, lifestyle and complementary therapy choices can affect the well-being of women following a diagnosis of breast cancer.

The quality of life scores that were obtained at the time of your recruitment onto DietCompLyf have been investigated.



We have studied how the quality of life varies according to age at diagnosis with cancer, the treatment received, lifestyle choices and support provided. The results showed that participants with an improved quality of life tended to be older at the time of diagnosis, they had not had chemotherapy, they exercised more than once a week, had a lower body mass index and drank alcohol responsibly. The analysis has shown that the factors which are most important for a higher quality of life include not feeling alone and having the practical and emotional support that patients feel that they need.

There are factors which influence quality of life that cannot be modified, including age for example. However there are lifestyle choices that can be made which may help improve quality of life. We intend to analyse this data further and to publish this in a peer-reviewed journal for others to read and hopefully base recommendations on the findings. Many thanks to all of you who continue to make this endeavor possible.

The results from this analysis were presented at the EORTC quality of life conference in October 2012 at the European Parliament, Brussels. News articles were also written on these findings – please see more details at the bottom of the page.



News articles from the European Association for Cancer Research conference have been published online at:

- www.saga.co.uk/health/news/2012/october/breast-cancer-patients-and-quality-of-life-350
- www.medpagetoday.com/HematologyOncology/BreastCancer/35434

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#### Patients' Questions & Comments

### Q: I don't feel up to having my blood taken this year, do I need to withdraw from the study?

We really appreciate any contribution to the study and you can just complete your questionnaires for this visit or take a break and carry on next year. Please just let your research nurse know if you would like to do this.

## Q: Some of the questions in the food frequency questionnaire are not relevant to me, can I leave them blank?

The food frequency questionnaire is used to find out what types of foods people eat and also to calculate everyone's average daily nutrient intake. The more answers that are completed the more accurate the data will be. On this occasion we would really appreciate it if you just ticked the "never" box.



#### Participants that have finished the DietCompLyf study



The Against Breast Cancer research group at the University of Westminster holds regular open afternoons where supporters are welcome to visit the research labs and meet the scientists behind the work. If you are interested in attending, could you please contact the Against Breast Cancer charity:

www.againstbreastcancer.org.uk/news/ charity-news/697/open-afternoons-atuniversity-of-westminster/

Tel: 01235 534211



Cumulative number of participants that have finished the DietCompLyf study

If you have reached year 5 on the study and would like to receive further annual newsletters with the study results, please complete your address on the form included in the year 5 questionnaire pack and return this with your questionnaires. Alternatively you can request this via email at: <u>dietcomplyf@westminster.ac.uk</u>

The current newsletter and earlier issues are available on the DietCompLyf website under 'patient newsletters'

www.westminster.ac.uk/research/a-z/against-breast-cancer/projects/diet-and-lifestyle

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