

The work of the Generations Study Communications Team

Sending letters to you and sending this Newsletter, as well as processing the questionnaires and forms that you return and answering your questions on the telephone, is handled by the Generations communications team. They are housed at the Sutton campus of the Institute in the newly built Sir Richard Doll Building, named after the epidemiologist who first showed that smoking causes lung cancer. The team came to work on the study from very varied backgrounds. Now they form a tight-knit team who ensure that the mailing proceeds smoothly. Each day the Royal Mail make a special visit to collect about 22 sacks of mail, with similar amounts of mail coming in. The team are also responsible for the storage of most of the blood samples, which are kept at very low temperatures in giant tanks in the basement of the Sir Richard Doll Building, as shown below.



Sandra, Gloria, Sharon, Chi and Gill with the day's post ready for the Royal Mail

It is one of the pleasures of working on the Generations Study, that the women who phone us are so positive and enthusiastic. That doesn't mean, however, that we don't get some fairly unexpected questions and tales. The most common phone calls are to ask us to send another copy of the questionnaire because the original one has been lost or damaged. Many of you seem to have dogs or cats that eat questionnaires, and a few of you seem to have children who do the same! More unusually, we have been asked for replacement questionnaires after a post office burned down, after the questionnaire was built into a house extension, and after destruction of the questionnaire by exploding cookery.



Sharon putting blood samples into a nitrogen tank

An unexpected consequence of the study

One woman who joined the study sent us a letter with a story that she rightly thought would cheer our day, and may cheer yours too. As a result of being asked in the questionnaire about the number of pregnancies her mother had before she was born, she asked her mother about this, and discovered to her amazement that her mother had had a son as a result of a wartime liaison, who was adopted long

ago. As a consequence, she now has a half-brother of whom she was previously unaware and her daughters have a new uncle and aunt and cousins. They are all delighted to have found each other and have now met up happily several times. We have to admit that this was not the purpose of the study when we set it up, but we were very pleased to hear about it.



This study is supported by the commitment and funding provided by the sponsors of the study:-
Breakthrough Breast Cancer (www.breakthrough.org.uk)
and The Institute of Cancer Research (www.icr.ac.uk).

Finally,

Thank you for your continuing support of the study. We are very proud that so many tens of thousands of women like you have been willing to give their time and effort to make it possible. We will write to you again next spring.

With all good wishes, **The Breakthrough Generations Study Team**

If you have not yet returned your questionnaire, or your blood sample.

If you have not yet returned your questionnaire or blood sample but would still like to participate in the study, it is not too late to join.

If you have not replied because you have a specific query, please contact us with your question and we will try to help.

Telephone **0208 722 4469** or write to:
Breakthrough Generations Study Team
FREEPOST NAT 21013
The Institute of Cancer Research
Sutton
SM2 5BR
(stamp not needed)

Similarly, if you have lost the questionnaire or blood pack and need another one, please get in touch and we will be happy to send you what you need.

WELCOME

Dear study member,

Another year has passed and we are pleased to be sending you the second newsletter of the Breakthrough Generations Study, investigating the causes of breast cancer. Since we sent the last newsletter, the study has progressed very well: there are now more than 73,000 women who are members of the study, with thousands more joining every month. We have also successfully started the first follow-up mailings to those women who joined earliest, during the pilot phase. This newsletter is to update you on the progress of the study and to tell you a little more about what the study is doing and why, about the women who have joined it, and about some of the staff working on it. We have also included some information on how we are preparing for the initial analyses from the study, and about a study that we are beginning on the causes of breast cancer in men.

We thank you very much for your contribution to the study, and look forward to writing to you again in the future.

With best wishes,

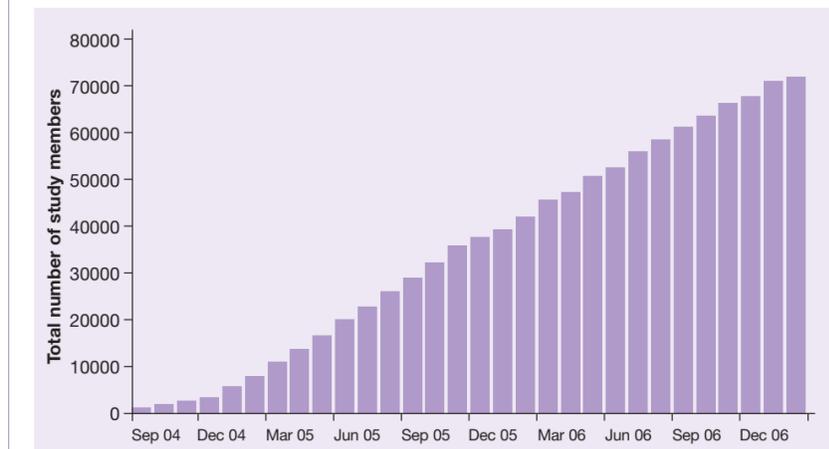
Professor Anthony Swerdlow

Professor Alan Ashworth

Progress of the Study

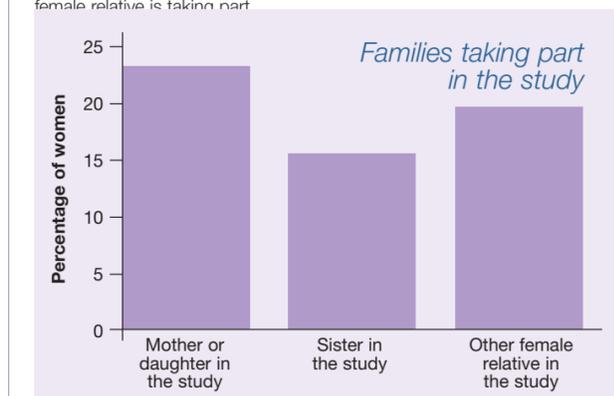
Recruitment of study members

The target for the Breakthrough Generations Study was to recruit more than 100,000 women as members within 5 years, and we passed the half-way mark to this, 50,000 women, in May last year, 20 months after the official launch. We are continuing to recruit new study members at a good pace, and over 73,000 women have now joined



2½ year follow-up

While recruitment continues, some women who joined the study earliest, during the pilot phase or at the launch, have now been part of the study for 2½ years. We are now sending a brief mailing to them, to ask about changes of address and any illnesses that they have had since they joined the study. You will be pleased to know that this questionnaire is short - less than 3 sides of paper - and shouldn't take long to complete. It also asks about whether you have relations who have joined the study, because an important objective of the study is to investigate family risks. From the replies we have received so far, you may be interested to know that for a quarter of study members their mother or a daughter is also in the study, for 1 in 7 a sister is taking part, and for 1 in 5 another female relative is taking part.



Progress of the Study

(continued from page 1)

The next steps

It will be several years, as you know, before we will be able to conduct direct analyses of how breast cancer risk relates to the factors in the questionnaire answers that you gave when you joined the study. We are pleased to be able to tell you, however, that we have now received a grant from Breakthrough to prepare data for analysis and then to start analyses of certain questions related to breast cancer that it is possible to investigate more quickly. The data preparation phase will include work to check whether the information in the questionnaires is consistent and plausible. If the questionnaire responses seem very unlikely, it is worth checking if there has been a misunderstanding or mistake. So, if you are one of the participants whose questionnaire appears to state that your children were born before you were, or that you have taken the oral contraceptive pill for 50 years, we hope that you won't mind if we contact you to check if there has been a mistake, and what the correct information is. Once we have corrected mistakes in the data as far as possible, we will be starting analyses – for instance to examine the extent to which factors that affect breast cancer risk, such as hormone levels, run in families. All of this will take some time because of the very large number of women in the study, but when we have the results we will let you know about them via these newsletters.

The Questionnaire: night work, sleeping patterns and breast cancer

The questions asked in the questionnaire are all there for a good reason, but in some instances the reason may be less obvious to you than in others. We thought it might be of interest, therefore, to explain in these Newsletters, from time to time, why some of the questions were asked.

Several of you have asked why there were questions about night work, sleeping patterns, and air travel. These questions relate to a theory first put forward 20 years ago, that breast cancer risk might be affected by a hormone called melatonin that the body secretes at night when it is dark. The hormone is known to be responsible for maintaining our 24 hour rhythm of sleep and wakefulness, and for the feelings of jet lag, but it is unknown, despite theories that have been put forward, whether it has any effect on breast cancer risk or not. We therefore asked you about various factors that might influence melatonin levels – including shiftwork, light exposure at night, air travel across time zones, and sleeping patterns – so that in years to come we will be able to determine whether or not these factors affect breast cancer risk.

Breast cancer in men

Although breast cancer is much less common in men than women, it does occur, with around 300 men diagnosed with this disease every year in the UK, and it is a serious disease for the men who suffer from it, just as it is for women. We have had enquiries from several of you as to whether men can join the Breakthrough Generations Study, but the design of the study is not suitable to find causes of breast cancer in men (it would need to include about 10 million men to be able to do so); therefore the study is solely for women. We are delighted to be able to report, however, that we are now starting, with funding from Breakthrough, what should be much the largest study anywhere in the world on the causation of breast cancer in men. The design of the study will be one in which we will be approaching men who have had breast cancer and a group of similar men who have not had breast cancer, and asking each to fill in a questionnaire and to give a blood sample. It will take several years to complete, and should, we hope, greatly contribute to finding the causes of breast cancer in men. It will also give some information of value for women: the risk of breast cancer is known to be raised in women closely related to men with breast cancer, but we need to find out, and will be investigating, whether this applies similarly to all such women or happens more in particular groups of them.

Study members from



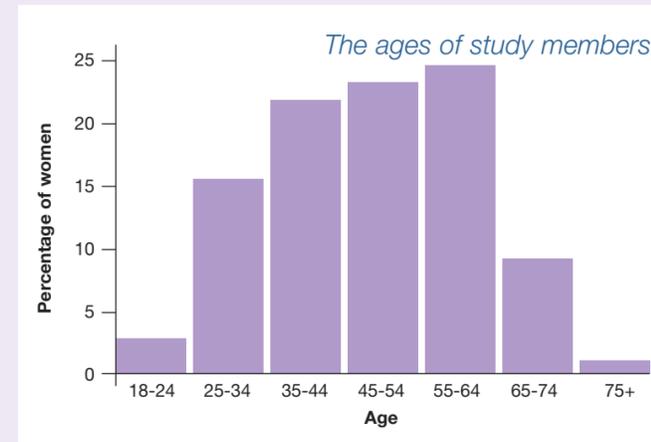
Ruth Hunter wrote to us from Inverness about how several of her friends at work have joined the study. The photograph shows Ruth (right), Jane Burns (left), and Donna Ross (centre).

Ruth wrote "A close friend asked me to take part in the study and when I told the girls at work I was overwhelmed by the interest and have ended up recruiting over 20 women so far to take part. There is no history of breast cancer in my family, but as a mother I saw it as important to do something for my daughter's generation. Sadly, just after agreeing to take part my great aunt was diagnosed with breast cancer. Luckily, she caught it early and her outlook is good".

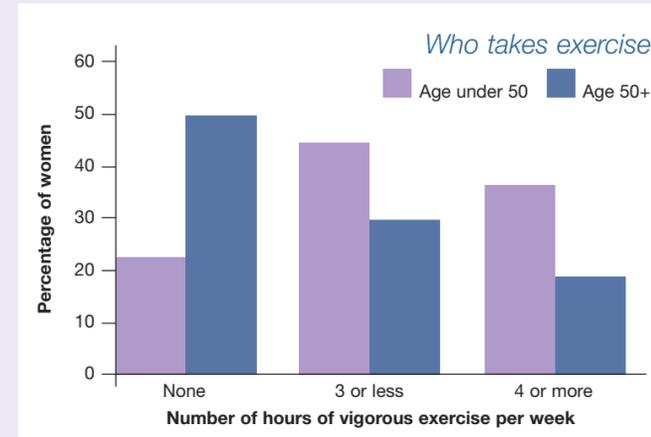
Jane Burns said: "When a good friend asked me to take part I felt it was a good opportunity to "do my bit". Having seen my aunt suffer from breast cancer I felt compelled to take part in this research – a blood test and a questionnaire is a simple way to help. This research will help future generations to beat this disease".

About you, the Generations Study members

The Breakthrough Generations Study members include women from every background and every part of the British Isles, from Jersey in the south to Shetland, about a thousand miles to the north, and from Lowestoft in the east to County Fermanagh in the west. About a third of you are aged under 40, almost a half aged 40-59, and a fifth aged 60 or older. The oldest member of the study is aged 98.

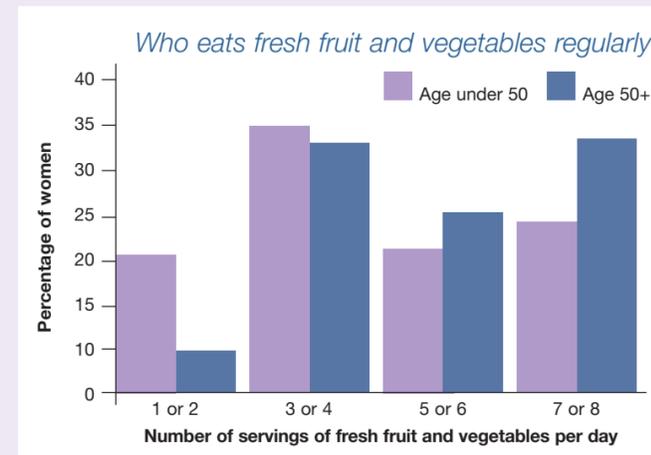


Based on a sample of your replies, almost a third of you exercise vigorously for 4 hours or more per week, a third for shorter periods per week, and a third don't take part in vigorous exercise. As you might expect, this depends very much on age: more than three-quarters of study members aged under 50 exercise vigorously compared with half of those who are older.



The proportion of you who have had a mammogram also varies greatly by age – 95% of study members aged 50 or older have had a mammogram, but only 10% of younger women. This is likely to reflect the fact that the NHS breast screening programme starts at age 50.

You may be more surprised to hear that eating fresh fruit and vegetables also differed by age: older study members are more likely to eat at least 5 portions of fruit and vegetables a day, and less likely to eat only 1 or 2 portions per day, than younger members, as you can see opposite.



All of this, of course, is based on an early sample of questionnaires; we will need to look at it again later, from the whole study membership, but we thought you might be interested in the meanwhile to get some preliminary information.

Has your name, address or telephone number changed?

If your name or address is different from that on the newsletter envelope, please detach and return this reply slip in an envelope addressed to:

Breakthrough Generations Study Team
FREEPOST NAT 21013
The Institute of Cancer Research
Sutton
SM2 5BR
 (stamp not needed).

Please enter your study number (which you will find next to your address on the envelope containing this newsletter), and your date of birth, so that we can be absolutely sure that we are updating details for the right person.

If the details on the newsletter envelope are satisfactory to reach you, there is no need to return this slip.

BLOCK CAPITALS PLEASE

First Name(s) _____

Surname(s) _____

Address _____

Postcode _____

Telephone Number _____

Date of birth
 Day _____ Month _____ Year _____

Study number _____
 (the 6 digit number next to your address on the envelope containing this newsletter)