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 2103
The Institute of Cancer Research
Sutton
SM2 5BR

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.

My mum was diagnosed with breast cancer whilst I was away at University. I am not sure whether it was brought away from her or her impressive positive attitude, but somehow I never really acknowledged the severity of her illness until after she was well into her recovery. A few years later, to everybody’s surprise (especially that my father was also diagnosed with breast cancer. As with my mother, I appreciated everything with optimism and a sense of humour. Despite the trials, however, I felt there were additional issues that he faced. Most obviously it affected his pride and masculinity, but at times he acted like he was repossessing an area that was supposedly out of bounds. After a masculinity, chemotherapy and radiotherapy, he was back on the top form. They make a point about the appointment with their consultant, swap Testoviron at the breakfast table and are still smiling. Although I did make a few early complaints about the food, but I can’t help but wonder how much of the questions intriguations we can ignore. The blood test was fine, quick and easy, and you can always look the other way if you don’t like that sort of thing.

As a volunteer, I encouraged one of my friends to join the study. We found it easy to fill in the form, although some of the questions were slightly intrusive. The blood test was fine, quick and easy, and you can always look the other way if you don’t like that sort of thing.

So, if you know anyone else who would be willing to volunteer, please don’t hesitate to ask them. It’s an excellent cause and it will be interesting over time to learn of the findings that may help prevent cancer.

The funding of the Breakthrough Generations Study: £12 million target reached

Studies such as the Generations Study cost a great deal of money. You may be interested to know that Breakthrough Breast Cancer recently achieved its target of raising £12 million for the initial years of the study, the funds coming from a generous Brian Davis and Diamonds Ball held at the Park Lane Hilton. We are grateful to Breakthrough and all their supporters and donors for the funding that has made this study possible. The study is also supported by the Institute of Cancer Research, to whom we are also grateful.

We will be continuing to recruit women to the study for at least another year or more, so if you have received the questionnaire and not yet returned it, or if you know of friends or family who would like to join the study, it may be any time now. Pilot study recruitment very successfully, with more than 20,000 further women joining. Dawn Thomas and her team at Sutton have been working hard to mail questionnaires to new study members, and to process the mail that you return. Recently they have also started to send out brief follow-up questionnaires to those of you who joined the study earlier, in 2003-04, Germaine Simpson and her laboratory team have meanwhile been processing the thousands of blood samples received at the laboratory and then storing them in the liquid nitrogen tanks. We intend to recruit for at least another year, and to continue well beyond 100,000 women.

As you may remember, the design of cohort studies such as this one, is that once people enter the study, information about their past and present status is recorded, and then over the following years, we continue to follow-up and record details of any illnesses or deaths. This applies just as much to those women who don’t develop illness as to those who do, because we need to know who does and who doesn’t.

We all found it easy to fill in the form, although some of the questions were slightly intrusive. The blood test was fine, quick and easy, and you can always look the other way if you don’t like that sort of thing.

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.

Finally,

Thank you, as ever, for your continuing support of the Generations Study. We are grateful to all of you whose participation makes the study possible.

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

Stephanie Payne with her parents, Elitee and Juliet

Sue Carless left and away Bruce (right), who introduced her to the study.
Progress of the study over the last year (continued from page 1)

we don’t have to send you another copy, and we can start gaining results from the follow-up as quickly as possible. The success of the study in finding out what causes and prevents breast cancer depends on gaining information from as many women as possible. It is really important that your details are correct since you joined, so please tell us if your name, address or phone number has changed.

We are pleased to be able to tell you that the first PhD student working on data from the Generations study, Danielle Morris, started work with us in October 2007. She will spend the next four years with the study team at The Institute of Cancer Research in Sutton, using the information you have sent to us to analyze factors that may affect breast cancer risk. She originally studied mathematics and economics at Nottingham University, and then moved on to a computer science and mathematics degree at Lancaster University, so she is very well qualified to analyze the data.

She writes: “As soon as I heard about the study I wanted to be a part of it. It is true that the opportunity to work on something that has the potential to really change things, has never occurred to me in cancer research since I first heard about cancer. I also think that the huge support from all the women who have joined the study shows that breast cancer affects everybody and is a topic that is important to many of us, as much as possible about it. It is fantastic to be working on something that is in the cutting edge of research with people who are experts in the field. As I am starting my research career it is an excellent chance for me to learn from them.”

One of the good things about the Generations Study is that often several members of the same family have joined. Mothers have recruited their daughters, sisters have recruited each other, and so on. The most frequent relationship is mother and daughter. The largest number of generations within the study that we know about at present is three. There are more than 500 families where a grandmother, mother and daughter all join the study. If there is a four generation family who have joined, we would be very pleased to hear from them. If there is a member of your family who would like to, we would be happy to send them information packs. To enable this, please phone 079 314 34480 or go to www.breakthroughgenerations.org.uk.

Inclusion of young women in the study

When you joined the study, the age range of women being recruited was 18 years and above. We have since received many enquiries from study members as to whether their young daughters aged under 15, or other young women their daughters or they know, could join the study. We are pleased to be able to say that after correspondence with the Ethics Committee, it has now been agreed that women aged 15 and above can join. If you, or your daughter, or any other young women you or they know, are aged 15 and above and would like to join the study, we would be very pleased if they did so. The question should take them much less time to complete than for older women because, as you will recall, many of the questions take longer if you have more life experience. Nevertheless, their contribution would be scientifically very valuable in this area, as we, in life general, the young are still to the future.

We have also compared mothers and daughters, where both have joined the study. More than half of daughters are at least an inch taller than their mothers, and more than half of mothers are heavier than their daughters, as shown in the two graphs below. About two-thirds of mothers have a higher weight for their daughters, but not everyone is the same – perhaps you are one of the few who are much taller and slimmer than your daughter?

Danielle Morris

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
FREDERICK MAT 2012
The Institute of Cancer Research
Sutton
SM2 5AU
[stamp not required]

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.

If you have any queries about this newsletter, please phone 0870 242 4485 or go to www.breakthroughgenerations.org.uk.