

Factors Associated with Childhood Tumours (FACT) study

INFORMATION SHEET FOR CHILDREN AGED OVER 14

We would like to invite you and your mum and dad to take part in our research. We are trying to find out more about the causes of childhood tumours.

What is the purpose of the study?

There are two aims of the study:

- 1) We want to identify genetic factors that increase the risk of developing a tumour in childhood.
- 2) We want to know more about the medical conditions that can occur together with childhood tumours.

We already know some of the faulty genes that can lead to childhood tumours. We think there are many other genes involved. We think faulty genes may be a factor if a child has another medical condition as well as the tumour, or if the child has more than one tumour.

Why have I been chosen?

We are asking families to take part if a child in the family has a solid tumour, or a medical condition as well as a tumour, or more than one tumour, or relatives with tumours, or lots of side effects from their treatment.

What will happen to me if I take part?

If you agree to take part we will ask for a small sample of blood from you and your mum and dad. You may have already given a sample that we can use, in which case we will not need another one. We will try to take the sample at the same time as you are having another sample taken so you will not need an extra needle. We will also ask your Doctor for medical information about you and access to tumour samples. We will use the samples and information to try to find faulty genes that can increase the risk of tumours. We will give the samples and information a special code so no one will know who you are. We will keep everything locked in a safe place.

Do I have to take part?

It is up to you whether or not to take part. You can stop taking part at any time, without giving a reason. If you decide to take part, your mum and dad will be asked to sign a consent form. They will be given a copy of this information sheet and the consent form to keep.

What are the possible benefits of taking part?

We may be able to find out a possible cause of tumours in you/your family. If this happens, you may decide to have a test to see if the faulty gene caused your tumour. Before having a test, you and your mum and dad would have to discuss things carefully with your Doctor and you may have to give another blood sample. For most people who take part we may not find a specific faulty gene that has caused tumours in the family. But the research should help us understand more about the causes of childhood tumours generally. This may help other children in the future. The research may take many years.

What are the possible disadvantages of taking part?

We do not expect any disadvantages from taking part.

What will happen to the results of the research?

If we discover new things about how childhood tumours are caused we will publish these in medical journals. You will not be personally identified in any publication. If there are results that are important for you personally, we will tell your Doctor. No results will be sent directly to you or your family.

Who is organising and funding the research?

The research is being organised through the Children's Cancer and Leukaemia Group (CCLG) and is funded by The Wellcome Trust. Professor Nazneen Rahman and her research team are doing the research.

What if I have any concerns?

If you have any questions about this study please contact:

FACT Team
Section of Cancer Genetics
Institute of Cancer Research
15, Cotswold Road
Sutton, Surrey
SM2 5NG
Tel: 0208 722 4099
Fax: 0208 722 4359
Email: grs@icr.ac.uk

Thank you for reading this.