Cancer Genetics Clinic

Information for patients coming to the North East Thames Regional Genetics Service

Great Ormond Street Hospital for Children NHS Foundation Trust

This leaflet explains about the Cancer Genetics Service based at Great Ormond Street Hospital (GOSH), what to expect when you come for an appointment and what type of information you can provide in order to get the most from your appointment. This service covers North East London and Essex and deals with adults and children.

Why have a Cancer Genetics Service?

One in three people will develop cancer at some point in their lives. Cancer can be caused by many factors but we divide them into two types: cases that happen by chance (sporadic) and cases where there seems to be an inherited component.

The cancer genetics service aims to determine whether there is a history of the inherited type of cancer and whether there is a risk of this being passed down through the generations.

Who are the Cancer Genetics Team?

The cancer genetics team consists of genetic consultants, a specialist registrar, and genetic counsellors, the research team. You may be seen by any one or more of them in clinic.

Who can attend this clinic?

There are two groups of people who tend to be referred to this clinic:

- Those who have several relatives diagnosed with cancer and are worried about developing it themselves.
- Those who have had cancer and are worried about their children or relatives developing it in the future.

How do I know if I have the inherited type of cancer?

You will be asked to fill in a family history form.

There are three categories we look for to help us in determining your risks:

- The size of the family, and how many people have had cancer – having more affected people in the family than we would expect to see in the general population increases the risk that the cancer may be inherited.

- The age your relatives were when they developed cancer – generally, the younger they were at diagnosis, the greater the risk.
- The types of cancer and the pattern within the family – some types of cancer are linked and are more likely to be due to an inherited cause. Other types are less likely to be inherited.

What happens next?

Once you have answered the questions about your family history, we will have a better idea of the risk you or other family members have of developing cancer.

In some families, we will discuss the possibility of testing for a gene alteration that increases cancer risk. This is not always available, and it can be difficult to identify the altered gene in some families.

We may recommend screening for at risk individuals in a family to detect cancer early. This may be offered even if there is no genetic test available. So it is worth talking to us about your cancer risk and the pros and cons of screening, even if we are not able to offer you a gene test.

Finding a gene alteration

Our genes can be thought of as a code, made up of a long string of letters. If one of these letters is out of sequence, the gene is said to be altered. This error can be anywhere along the string of letters, so it can take a long time for the laboratory staff to identify it.

Our genes are the instructions for our body's make up. We are all born with all our genes, and they determine how we develop. A few of these genes are involved in protecting us from cancer. If there is an alteration in one of these genes, it is unable to work properly, and so some of that protection is lost.

If a gene alteration is found it does not necessarily mean it will be passed on from generation to generation. The risk to family members of inheriting it will depend on the type of cancer and the pattern within the family. In the majority of cases even if the altered gene is inherited, this does not always mean that the person will develop cancer, just that their risk is increased.

In order to carry out gene testing, the laboratory staff usually need a blood sample from a living relative who has had cancer. Once an alteration has been found, it is more straightforward to test their relatives for the same alteration. Even if you have no living affected relatives we still may be able to help arrange screening for you, and discuss alternative options if possible.

Getting the results

Due to the lengthy process involved in analysing a blood sample for a gene alteration, it can take approximately two to three months for results to come back. If a gene alteration is discovered, we will contact you or your relative to explain the results and your options further.

If you have any concerns about your appointment please call 020 7762 6786 or 020 7762 6831.

Are there any support groups?

Macmillan provides up to date information, practical advice and support for cancer patients and their families. Call their helpline on 0808 808 00 00 or visit their website www.macmillan.org.uk.

Ref: 2014F0593
Compiled by the Cancer Genetics Service
in collaboration with the Child and Family Information Group

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