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Royal Brompton & Harefield NHS
NHS Foundation Trust

Information regarding your Genetic Screening appointment for

Familial Hypercholesterolaemia (FH)

What is FH?

FH is a genetic disorder that leads to high levels of cholesterol in the blood. If left untreated, high cholesterol levels can increase the risk of developing heart disease or having a heart attack at a much younger age. In people with FH, high cholesterol levels are usually present from birth. FH is an inherited condition which means that the gene causing FH will have been passed on from one of your parents. If you or a member of your family is identified as having the FH gene, they also have a 50% chance of passing it on to their children. There isn't a cure for FH, but FH can be treated very successfully.

Why do I need to have genetic screening?

You have been invited to have genetic screening for FH because your Doctor or other health professional believes that you or a close relative may have inherited the gene alteration which causes FH. The initial diagnosis of FH is usually made following consideration of your cholesterol levels, family history and clinical signs. However, genetic testing enables us to identify the gene which may have caused your FH.

What can I expect at the appointment?

The appointment will take about an hour and you will be seen by a Clinical Nurse Specialist in FH screening. During the appointment you will be given a full explanation of FH and given healthy diet and lifestyle advice. You will need to have a small blood sample taken for genetic screening analysis. **You are not required to fast for this test.** These results and the process with which you will receive them will be explained to you but you can expect them to take about 2 months.

How can I prepare for the appointment?

During the appointment the nurse will ask you about your family history in order to draw a family tree. It will be useful if you can prepare for the appointment by asking family members (mother, father, aunt, cousin etc.) whether they or any deceased relatives, have suffered a heart attack, stroke,

cardiac surgery or raised cholesterol. It is also useful to have a vague idea of their ages when any of these illnesses were first diagnosed. We have included a form with this letter to help you record this information.

What are the benefits of this screening?

Having genetic screening for FH will not alter your current treatment. If you already take medication for raised cholesterol that will continue, however a genetic diagnosis will help your doctor to decide if you are on the right treatment. If you receive a positive result for FH from your genetic screening test it means that we will then be able to identify and screen family members. This will enable them to receive appropriate treatment and support if necessary where they would otherwise be at risk of developing heart disease or having a heart attack at a much younger age. Starting treatment early, before coronary heart disease is established can greatly reduce your risk of dying prematurely.

If you wish to know more about FH please visit www.heartuk.org.uk or www.bhf.org.uk. We strongly advise that you ask any questions you may have when you see the nurse specialist for your genetic screening appointment.

Please do not hesitate to contact us if you have any questions prior to your genetic screening appointment. If you are unable to attend your appointment please do let us know in advance so that your appointment can be offered to someone else who may be waiting.

Familial Hypercholesterolaemia (FH) Genetic Screening Service

Royal Brompton and Harefield NHS Trust

01895 823737 ext. 85084 or 0330 128 3737 ext 85084

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Family History Form

Please complete this form to the best of your knowledge and take it along to your appointment with the FH screening nurse.

You should list all first degree relatives which include your parents, siblings and children.

Do not worry if you are unable to answer all the questions accurately as a vague idea will suffice.

Name	Age	Relationship to you	Raised Cholesterol? (include result if known)	Are they taking cholesterol lowering medication?	Is there a history of heart attack, angina and stroke?	Further information

Please only use this section to record the medical history of any deceased relatives where known

Name	Age when died	Cause of death (if known)	Relationship to you	Raised Cholesterol? (include result if known)	Is there a history of heart attack, angina and stroke?	Further information