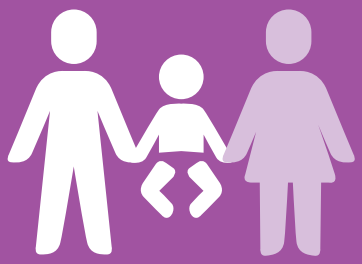
The AHSN Network

Child Parent Screening Service Information for Parents

A new screening service to identify children and their families with familial hypercholesterolaemia (FH), a genetic condition that causes very high cholesterol and can lead to heart attacks at a young age, is now available in this practice. Over 10,000 children have been screened as part of a research study. During a pilot phase:

4 in 1,000 children screened were identified as having FH



At least 1 parent will also be positive if the child receives a diagnosis of FH

If you have a child around 1-2 years old who is due their routine immunisations, you will be invited to have your child screened for FH; the test involves a simple heel prick and takes less than 2 minutes. The test measures the level of cholesterol, if the cholesterol level is high a further sample will be sent for a confirmatory genetic test.

Please ask at reception for further details.
You do not have to take up this offer of an additional test.

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Further information
The genetic testing aims to identify the faulty gene linked with FH. If the test is positive, the child will be offered dietary advice as early as possible and also treatment. The local FH Cascade team will be alerted as for every child with FH - one parent will also have the faulty gene. Adults with a positive test for FH will receive statins immediately. If the initial heel prick test was positive but the genetic test was negative, the child will need to re-tested within a 3 month period.

Frequently Asked Questions

What is Familial Hypercholesterolaemia
Familial hypercholesterolaemia (FH) is an inherited condition which results in very high levels of cholesterol in the blood.

About 1 in every 250 people have FH and affected individuals have a high risk of developing heart disease at a young age.

They have about a 100-fold increased risk of a heart attack before age 50. Treatment with cholesterol lowering drugs (called statins), is effective in reducing this high risk, so this service offers an opportunity to prevent heart disease at an early stage.

Recent research shows that it may be possible to identify most children who have FH (about 90%) using a simple heel prick blood test at about 1 year of age.

Measuring cholesterol at birth, later in childhood or in adulthood is less accurate. Measuring cholesterol at about 1 year of age offers a window of opportunity to identify most cases of FH in the population without falsely diagnosing the condition in a large number of people.

How is Familial Hypercholesterolaemia inherited?
FH is a condition that can be passed on from each generation to the next. Both men and women can inherit FH and will be affected by high cholesterol levels without knowing it. On average half of all children of an affected parent will also have FH. For example, in a family of four children where one parent has FH, two of the children will also have FH. It follows that a child with FH will have an affected parent. Screening children therefore presents the opportunity to also identify parents with FH, by measuring their cholesterol levels, and if affected to reduce their risk of heart attack.

Will I hear about the result of the blood test?
Yes, the test result will either be "negative" or "positive". If the result is negative, no further action is required. If it is positive both parents and child will be invited back to the General Practice to discuss the results and arrange confirmatory blood tests and parental screening.

In a very small number of children (less than 1%), we may find a very high cholesterol and a negative genetic test (no FH mutation) because not all mutations are known.

These children will need one more heel prick in about 3 months time to see if the cholesterol was genuinely very high or just a false reading.

What treatment will be offered to children and parents (if positive)?
In children who have FH, it is important to introduce a healthy diet as early as possible. Medication to lower cholesterol (statins) is not usually needed immediately but will be offered when he/she is older – usually at about 8-10 years of age.

Treatment with statins would then be started. Until this time, life-style measures to remain active and keep a healthy diet are needed and advice will be given on this. In parents who have FH, treatment with statins will be started immediately.

These are widely used, safe and effectively reduce the risk of heart attack. Statins are well tolerated and extremely effective in reducing the high risk of heart disease. Parents who have been taking statins for several years will be familiar with what they involve, simplifying the start of treatment in the children when the time comes.

What will happen to our medical records?
The results of the cholesterol test and any medical records will be kept confidential. No information identifiable to any individual person would be made public.

Please read this information leaflet and ask any questions you may have, either ahead of your visit by calling the CPS helpline on 0191 249 6412 or emailing nationalcpsshelpline@ahsn-nenc.org.uk, or when you are seen at the Practice.