



The Royal College of Surgeons of England

wellcome trust



Genetics of Otitis Media Study

Information Sheet (Child/Young Person 11-15)

Version 1, 9th September 2008, Mahmood Bhutta

We are asking you if you would like to help us with some research. Your brother or sister has developed inflammation (swelling) in their ear, which doctors call “otitis media”. Doctors treat this by putting a tiny tube (called a grommet) in your brother or sister’s ear.

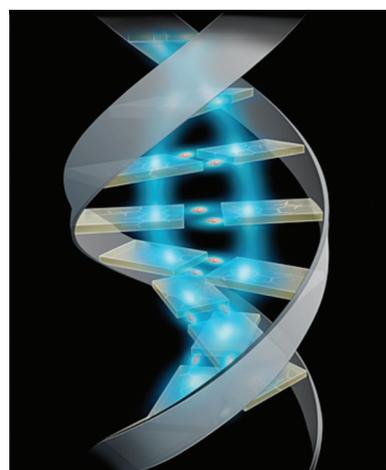
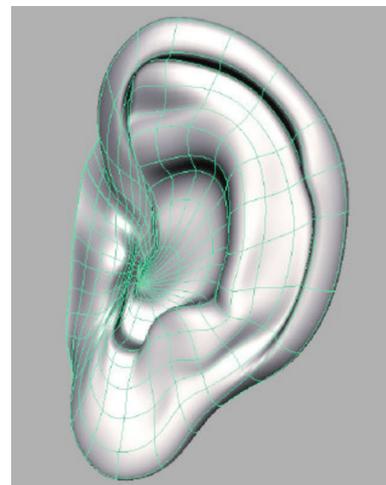
Doctors don’t know why ear inflammation happens. We do know that this problem runs in families. This means that there must be something in the DNA of your family that makes your brother or sister develop ear inflammation. DNA is a chemical found in all the cells of your body that tells your body how to grow, or how to function. The doctor looking after your brother or sister wants to test the DNA of your family to see if they can find out why this has happened.

Before you decide if you want to join in it’s important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk about it with your family, friends, or the doctor if you want to.

Why have I been chosen?

You have been chosen because your brother or sister has developed ear inflammation, which we will be treating. You have DNA that is similar, but not the same as your brother or sister. Finding out how your DNA is different to your brother or sister’s, and how it is different to that of other people, might tell us why this problem has happened.

Doctors are testing 1,000 families in this way.



Do I have to take part?

No. It's up to you. If you do, we ask you to sign a form giving your consent or assent (your mum or dad will also be asked to sign). You are free to stop taking part at any time during the research without giving a reason.

What will happen if I take part?

If you do decide to take part we ask that you give us a little sample of saliva (spit) in a pot. This is really easy and painless. You can do it yourself. You can give the pot of spit to the doctor, or you can post it to us.

Doctors can get samples of your DNA from your spit and do tests on this. Doctors would also like to keep a sample of your spit to do more tests in the future. They will only test the DNA from your spit for problems that might cause ear inflammation and not for anything else.

What are the possible benefits of taking part?

There is not really any benefit to you in taking part. But, your sample of DNA will help us to understand why ear inflammation happens, and we might be able to do to stop other children getting this problem in the future.

What happens if something goes wrong?

It is very unlikely that anything serious will go wrong. If you think something has gone wrong you can talk to the doctors at the hospital or contact the research department at the hospital.

Will anyone else know I'm doing this?

All the information you give us is stored in a high security computer. Your saliva sample will be stored at a separate laboratory with its own security system. Nobody except the research team will have access to your data or your saliva sample. Nobody else will be told that you are taking part in this research.

Has anyone approved this research?

Before research happens it has to be approved. This research has been approved by the Oxfordshire Research Ethics Committee and by your local hospital's research department.

What if I want to know more?

If you want to know more, speak to the doctor looking after your brother or sister. You can also contact the nurse who is in charge of the research – your parents have the contact details.

Thank-you for your help