

INTRODUCTION TO DNA AND GENES

Our genes play an important role in defining many characteristics about individuals and some can make us more or less likely to develop many common diseases. We all have a slightly different set of genes in our bodies. To help us look at these differences and understand varying characteristics and the causes of diseases, we can use a number of techniques to obtain samples of DNA from blood or tissue samples. The study of DNA and genes is referred to as genetic research.

WHAT ARE GENES AND DNA?

Genes are the instructions which determine growth and development of all living organisms. DNA is the chemical language in which genes are written.

WHY DO YOU WANT TO STUDY MY DNA?

Although we all have essentially the same genes as each other, there are many small differences which some of us have and others do not. These different versions of our genes can make us more likely or less likely to develop many common diseases, such as allergies, asthma, diabetes or heart disease. It is not our genes alone that cause disease, we already know that many of our common health problems are partly caused by genes and partly by our environment so we will be looking at your DNA along with other information you give us by questionnaire and at clinics to understand how these diseases occur and how they could be treated in the future.

HOW WILL OUR DNA HELP?

Children of the 90s has been collecting DNA from participants over a number of years and COCO90s now hopes to collect DNA from the children and partners of our original children as well as continuing to collect from our original participants. By having DNA from all members of many families enables us to look at all the different sets of genes, how they are inherited and which ones may be connected to different diseases. We do this by looking at the DNA in a specific gene that we are interested in or by looking at all the genes that a person has.

HOW DO YOU GET A SAMPLE OF DNA?

We can get DNA in several different ways. We can extract DNA from cells in your blood or saliva or we can also take it from cells in samples of placenta or umbilical cord.

WHERE IS MY DNA KEPT?

Your samples, including the main stocks of any genetic material collected such as DNA, will be stored in Bristol Bioresource Laboratories, University of Bristol. A lot of the research using your samples will take place in Bristol but some of your samples may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad. We may ask for a fee from researchers to help cover the costs of storing your samples as well as the costs associated with sending them to other places. We will not sell or make any profit from the samples you donate and they will only be used in ethically approved research.

FREQUENTLY ASKED QUESTIONS.

Q: WILL ANYONE BE ABLE TO CONNECT THE RESULTS OF GENETIC TESTS TO ME?

A: No. All the information in the COCO90s study is kept separate from your name. No one who works with samples is allowed to know who they came from. This personal information is completely confidential.

Q: WOULD YOU EVER SELL MY DNA?

A: No, we would never sell these, or any of the information you have given us.

DO I HAVE TO GIVE A SAMPLE OF DNA?

No, at your visits we will discuss all the samples we wish to collect with you and you will be given four options for each sample

- 1) You can decline to give a sample
- 2) You can agree to give the sample but only for a specified set of analysis and then the remaining sample will be disposed of
- 3) You can agree to give a sample for all specified analyses and storage for future non-genetic research (i.e. we will never extract or analyse your DNA but other analyses we do are still extremely valuable for scientific research)
- 4) You can agree to give a sample for all specified analyses and for storage for future research including DNA extraction and detailed genetic analyses

As with all other COCO90s research this is voluntary and if you choose not to give permission to use your DNA for genetic research this will not affect your continued participation in COCO90s or Children of the 90s

IF I CHANGE MY MIND LATER AND DON'T WANT YOU TO KEEP MY DNA WHAT SHOULD I DO?

You can change your mind at any time. Write to us and say you don't want us to keep your DNA or cells. We will remove the main stocks and destroy them.

CONTACTS AND FURTHER DETAILS

If you would like to contact us for further information or have any comments regarding this study please contact the study team:

Tel: 0117 3310039

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