



What is DNA?

Almost all cells in your body have DNA, and cheek cells are very easy to get. You can collect these cheek cells by rubbing a cotton-bud inside your mouth. Knowing this, we have developed a very easy way of collecting DNA, where we can send you special "DNA packs" by mail; you will collect cheek cells, put them in the tubes with special liquid and just send them back to us in the prepaid envelope provided. The packs do not last forever - but they are surprisingly robust.

Who is funding us?

The study is funded and regulated by the Medical Research Council independent of any commercial interest and is concerned with research only. You can be assured that nothing will be passed to the private sector and that all DNA collected will be destroyed at the end of the study. As a research study we are not allowed to pass on individual results apart from our "Zygoty test" which determines whether any set of twins are identical or not. We will however tell you about our research progress through our newsletters.

What are genes?

Genes are like recipes written in tiny strands of DNA, and they provide information to help make us who we are. We all have thousands of genes, and each of us has our own complex set of genes. It is well known that identical twins actually share the same genes - non-identical twins and other siblings share a lot, but not all. Genes have a major influence on what we look like, the colour of our eyes and our hair, how tall we are, and so on. Genes also have a partial influence on many other aspects of development, usually making little differences and sometimes causing problems. Genes certainly don't explain everything - but they are important to look at when trying to understand the interaction of genetic and environmental influences on development.

Zygoty testing

The purpose of zygoty testing is to determine whether or not twins are truly identical; that is, derived from a single fertilised egg (monozygous, **MZ**), or non-identical, being derived from two independently fertilised eggs (dizygous, **DZ**). Whereas MZ twins are genetically identical, DZ twins share on average only half of their genes, inherited from their parents.

The zygoty test used by the Research Centre is based on analysis of a series of sites at different points along the DNA molecules which carry the genetic information. These sites are chosen because they usually differ between people and are referred to as **DNA markers**. Because DNA is passed from parents to their children in a very specific and well understood way, analysis of these DNA markers can give very accurate information about whether twins are MZ or DZ. A parent will generally have two different versions of each DNA marker, but can only give a single version to each child. Therefore, the child will also have two versions of the DNA marker, one from each parent. For any single DNA marker, brothers and sisters may by chance inherit the same set of variant forms, but on average only half of the marker types will be shared by siblings, including DZ twins. But MZ twins will have identical versions of DNA markers.

With this in mind, we use automated technology to examine twelve such DNA markers simultaneously. We compare the results for all the twin pairs that we are asked to examine. If a pair of twins have all twelve marker types in common, we can be fairly sure (with only a very

tiny chance of being wrong) that they are MZ. If one or more pairs of markers are different between the twins, we can be sure that they are DZ. These DNA based tests are extremely reliable and to our knowledge have not resulted in a false labelling of MZ or DZ twins for any twin pairs examined so far.

What will be done with our DNA?

DNA samples will be deep frozen, in a special locked freezer that belongs to the TEDS Study. No names will be on the test tubes we freeze, only identification numbers. Before any scientists can use the DNA for research, their research must be approved in writing by the TEDS director, Professor Robert Plomin.

Could our DNA be used for cloning?

Absolutely not.

Can our DNA ever be used in police investigation?

No. The TEDS DNA bank will always be kept completely confidential, without exception. In addition, if a criminal court ever wishes to conduct a DNA test, they can easily take their own DNA sample from saliva, so there would be no need for them to contact TEDS. The TEDS DNA bank will be used only for research purposes.

Can my twins' DNA ever be used to test for who is their father?

No. The TEDS DNA bank will always be kept completely confidential, without exception. In addition, if a family court ever wishes to conduct a paternity test, they can easily take their own DNA sample from the alleged father's saliva, so there is no need for them to contact TEDS. The TEDS DNA bank will be used only for research purposes.

Can our DNA be used to predict if we will have future children with health problems (such as Down's syndrome or spina bifida)?

No. DNA is not used by doctors to test for genetic risk to unborn babies. The health of unborn babies is tested in a different way. Families who are concerned about their babies' risk can ask their GP about pregnancy testing and genetic counselling.

Can our DNA be used to test if family members will develop a disease later in life (such as breast cancer or Alzheimer's disease)?

No. TEDS DNA samples will not be analysed for any individual person. The DNA will be used by TEDS scientists to compare groups of people. For example, we will compare the DNA of all the children with reading problems versus those without, or all those who have experienced hyperactivity versus those who have not. The research will not yield any useful test result for an individual. We will not use your DNA to test for genes whose risk is already known, such as the breast cancer gene. The goal of our research is to search for possible new genes, but these would have to be confirmed by other studies before it is known if they are medically useful. If there is a gene that is already used medically to test an individual's risk for a disease, families can ask their GP about testing them for it.

If someone asks if I or my twins have had genetic screening, what should I say? You should say you have not had genetic screening, as we are not conducting screening tests on the DNA.

Can my GP contact you to find out the results of our DNA?

No. The TEDS DNA bank will always be kept completely confidential, without exception. The TEDS DNA bank will be used only for research purposes. If your GP ever wishes to conduct a DNA test for you, the GP can easily take a DNA sample from your saliva or blood so there is no need for GP's to contact TEDS.