



**Twin Research &
Genetic Epidemiology Unit**

Twin Research Unit

Information Leaflet

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Website: www.twin-unit/umds.ac.uk

INTRODUCTION

The Twin Research Unit was set up in 1992 at St Thomas' Hospital in London to look at the effect of genetic and environmental factors in the development of rheumatic diseases in older women.

The work performed showed that these bone diseases do run in families, and generated a great deal of interest in the value of twin research. The high quality of this research has led to continued funding of the St Thomas' UK adult twin registry. It has been extended to all adult twins and is now the largest registry of its kind.

The unit is now looking at many diseases associated with ageing, including – but not limited to – Osteoporosis, Osteoarthritis, Asthma, Diabetes, Cardiovascular diseases, Skin conditions, Eye disease etc. All twins volunteering for the study should receive a detailed disease survey questionnaire and some twins will be asked to attend.

Undertaking genetic research is expensive and we are fortunate, therefore, to receive funding and other assistance from many charities including the Arthritis and Rheumatism Council, the British Heart Foundation, the Chronic Disease Research Foundation, the Wellcome Trust, as well as commercial companies such as Gemini Research Limited.

IMPORTANCE OF TWINS IN MEDICAL RESEARCH

Comparing identical and non-identical twin pairs gives us information on the importance of inherited and lifestyle causes and effects on disease development.

Identical twins have identical genes. By comparing their differences and similarities, hereditary and environmental characteristics can be distinguished.

Non-identical twins have genetic profiles as different as any other sister or brother, but, like identical twins, they are subject to similar environmental influences. For this reason they are especially important in medical studies as they allow any environmental differences as well as any differences in genes, and the effects of those differences, to be studied very accurately, allowing new genes to be identified. This, in turn, should assist in the creation of more effective methods of diagnosing and treating disease.

FACTS

Our research has shown that:

- ❖ Osteoporosis is 75% genetic
- ❖ Pain tolerance is due to upbringing
- ❖ Disc disease causing back pain is 60% genetic
- ❖ Familial diabetes is related to stomach fat
- ❖ Smoking alters skin thickness
- ❖ Genes control body shape
- ❖ Timing of menopause is genetic

WHAT DOES VOLUNTEERING INVOLVE?

- ❖ A day trip to London: You will attend together on the same day.
- ❖ A detailed interview with a research nurse going through your medical and family history.
- ❖ Extensive medical check-up include:
 - Bone Density Scan: The density or thickness of the bones in your lower spine, hip and forearm will be measured.
 - MRI Scan (if over 50): Spine and neck MRI will be undertaken to investigate the genetics of vertebral disc disease.
 - Skin Examination: The number of moles and distribution of freckles on your body, eye colour, skin condition etc are noted and a comparison made between you and your twin.
 - X-rays (If over 50): Hips, knees and hands x-rays will be undertaken.
 - Eye Disease Assessment: Aimed at investigating any evidence of cataracts (cloudiness of the lens) or changes in the retina.
 - Cognitive Function Test: Involves carrying out a number of learning and memory tests on a special computer.
 - DNA test: To assess whether you are identical or non-identical and analyse your genetic make-up.
 - ECG: Electro Cardiogram.
 - Lung Capacity Test
 - Blood Pressure Check
 - Cholesterol Check
 - Blood Tests
 - Urine Test

OUTCOME OF YOUR VISIT

Our aim is to forward all clinically useful results on to your GP within three months.

FINDINGS

It is hoped that this research will provide us and those parties from whom we receive funding, with knowledge that will assist in discovering methods of diagnosing, treating, preventing and curing the diseases we are researching, including the development and production of diagnostic kits and/or medication for diseases. You will not benefit financially from participation in the study, although the results of this study might be valuable for commercial and/or intellectual property purposes. By participating in the study, you will cease to own the sample data which you provided, although your identity and details will always be maintained as strictly confidential.

IF YOU WISH TO VOLUNTEER WHAT TO DO NEXT?

Please ring our admin team on **020 7188 5555**. Please be ready to leave your name, address and telephone number after the recorded message. We will get back to you as soon as possible.

FEEDBACK FROM OUR TWIN PARTICIPANTS

- ❖ “Always friendly, helpful and positive. This makes it a day out for us. The teamwork is excellent.”
- ❖ “Well organised and easy to understand.”
- ❖ “All the tests were done with the most efficiency and kindness.”
- ❖ “I valued the opportunity to learn more about my health.”
- ❖ “I felt I was doing something useful to help people and combined the visit with a tour of London.”
- ❖ “I had fun doing it and the staff were terrific.”
- ❖ “I found the visit very informative and it also made you feel a bit special.”
- ❖ “It is a privilege to be part of your research. Nice to think we may be helping someone, somewhere.”

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