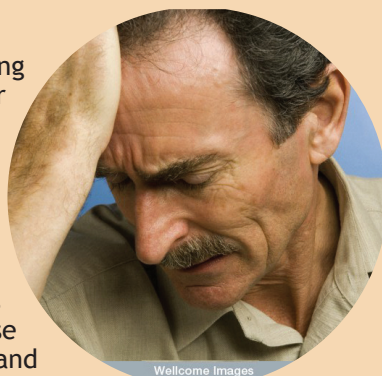


PAIN RESEARCH BREAKTHROUGH

For 22 years the Department of Twin Research has been collecting data on pain using questionnaires and sensory tests at twin visits, and DTR pain experts such as Dr Frances Williams have published over 15 important papers as a result. Dr Williams' latest paper describes two types of pain, previously thought to be unrelated. The first, neuropathic pain is a chronic type of pain that usually results from injury. The second type is chronic widespread pain, including fibromyalgia, which is a poorly understood condition with both physical and psychological symptoms. For the first time, it was discovered that these two types of pain are related through shared genetic risk factors and also shared environmental risk factors such as age, sex, weight, smoking, and socio-economic status. Researchers hope that these findings will lead to diagnostic tools and targets for the design of new drugs and treatments.



Wellcome Images

UNIQUE ADOPTION STORY

For the first time, TwinsUK members and identical twins, Claire and Jill, have told their unique story of adoption, loss and betrayal - which includes the discovery of their biological parents and results, unexpectedly, in another family adoption. It is a wonderful and emotional story. For those with internet access you can read the full story at www.twinsuk.ac.uk/twins/adoption-story



LINKAGE TO HEALTH RECORDS

The DTR uses twin data from questionnaires and visits for a wide-range of studies. In order to do this research, it is crucial that we have up to date and accurate health records, and for this reason we are linking twin data to NHS cancer and cause of death records. We are currently receiving data from NHS England (which covers Wales) and are now applying to NHS Scotland and also for linkage to NHS primary care records for all our twins. The importance of linking our data to NHS data was approved by the twin Volunteer Advisory Panel in 2009 and in 2014, and is included in the consent form that volunteers sign in order to agree to take part in our research. Permitting us to access health related records will help us discover how our health changes with time and to identify risk factors for developing disease later in life. Linkage to NHS cancer and cause of death records are currently provided by Health & Social Care Information Centre (HSCIC) a trusted government research service supported by the Department of Health. The process involves us providing in confidence names, dates of birth and NHS numbers in order to receive the data. Once the data is received it is anonymised and only the International Classification of Diseases (ICD) codes are provided to bona-fide researchers. Access to this data is strictly controlled and managed by Twin Resource Executive Committee (TREC) at the Department of Twin Research. Under the Data Protection Act 1998, we are fully compliant with all the legislation and security policies and procedures governing transfer, storage and use of data.



The Chronic Disease Research Foundation (CDRF), founded in May 1996, is a registered medical research charity which provides funds for research programmes at the Department of Twin Research that aim to uncover the risk factors for common conditions such as arthritis, back pain, migraine, dementia and heart disease. It is hoped that the findings will ultimately lead to the development of future diagnostic tests and new treatments. If you would like to consider donating to this charity or leaving money in your will to directly fund research at the Department of Twin Research, please visit www.cdrf.org.uk for more information or go to <http://www.twinsuk.ac.uk/codicil.pdf> to download the CDRF codicil (a document that allows you to make small changes to your will - such as adding a legacy).

KING'S
College
LONDON

Department of Twin Research & Genetic Epidemiology (DTR)

TwinsUK newsletter



April 2016

NEW TWIN VISIT

We are happy to announce that this month we are introducing a new twin visit, with some additional and extended tests, whilst keeping all the firm favourites such as the health MOT including bone mineral density, hearing test, eye tests and diabetes and cholesterol checks, and will continue to provide you with clinically useful results for you and your GP. Furthermore, and thanks to your feedback and that of our twin volunteer advisory panel, we have changed the format to provide a longer and more relaxed visit, with lunch on the house and the opportunity to meet other twins, all the while taking part in important research.



The new tests will cover diverse research areas such as eye-sight, oral health, and cognition. Our new eye tests will involve the examination of peripheral vision (side vision), important for road and general safety. Professor Hammond and his team will also examine the retina at the back of your eye which can be seen during a routine eye exam. A retinal exam is considered a window to our health and brain as it is the only place where arteries and veins can be seen close up without surgery. This could also provide very valuable health-related feedback. Our new cognition tests which explore different ways that the brain works will involve multi-tasking during simple tasks. And finally, some of you may be eligible for a short dental examination, the results of which we will also report back to you.

"Appreciated feedback of some of the tests on the spot."
"Extremely professional and friendly staff"
"Lovely fresh lunch, plenty of it and healthy."
"Nice chance to socialise with other twins over lunch"
"Day well organised and managed"

The dental examination aims to discover how oral health is connected to general health, as bacteria in the mouth can get into the rest of our system causing an immune response.

We piloted the new visit with a few twins and received some very positive feedback! (see photo above of the twins enjoying lunch)

Welcome to our 2016 newsletter. Last year many of our exciting discoveries were covered in the media



with more than 70 articles and radio programmes mentioning our research discoveries (see pages 2 and 3), and we reached a milestone number of twin visits ensuring that our research programme is as successful as ever. We have new storage facilities for our growing microbiome research samples and are about to embark on an exciting new twin visit. Thank you to all of you who have been in for visits, sent samples as part of the flora study or answered questionnaires. Every little bit helps and we couldn't do it without you.

Kind regards,

3000TH TWIN VISIT AND FUTURE PLANS

In 2015 we celebrated a land-mark 3000th NHS-funded twin visit (since 2012) with identical twins, Wendy and Gaye, in the state-of-the-art government-funded Clinical Research Facility in the Biomedical Research Centre (BRC) at Guy's and St Thomas' NHS Foundation Trust and King's College London. We were given this facility, because we, like the BRC are dedicated to 'translating scientific discoveries into improvements in treatment which will benefit patients at the earliest opportunity.'



But the most important thing about our research is to be able to compare results from one visit to the next (called 'longitudinal research'), especially in relation to our healthy ageing research. This will enable us to discover ways to improve our prospects for a healthier old age. We are currently in the process of writing a new grant so that we can ensure that twins can continue to take part in all aspects of our research over as long a time period as possible. This is particularly important for people who are no longer able to come in for research visits due to frailty or immobility. We will keep you posted about any new developments in this respect.

If you haven't been for a visit for four years and would like to arrange one, please contact us
020 7188 5555 | twinsuk@kcl.ac.uk

CHANGE OF DETAILS?

If we don't have your current email address or to update your contact details, please email twinsuk@kcl.ac.uk with your full name and date of birth or call 020 7188 5555

Department of Twin Research,
St Thomas' Hospital, Westminster Bridge Road,
London SE1 7EH
Tel: 020 7188 5555 | Email twinsuk@kcl.ac.uk

www.twinsuk.ac.uk twitter.com/twinsukres
www.facebook.com/twinsuk www.youtube.com/user/DeptTwinResearch

Major Research Sponsors: National Institute for Health Research wellcome trust European Commission Medical Research Council

TwinsUK Newsletter Editor: Juliette Harris

A SPECIAL TWIN VISIT

In December, we welcomed dedicated twins, Margaret and Kathleen to their 11th TwinsUK research visit. Margaret and Kathleen are 92 years of age and currently the oldest twins to come for a visit. Since 1993 they have taken part in every available study. During this time, between them, they have donated



2 litres of blood to research, given nearly 80 hours of their times, and filled out 30 health questionnaires. Our research success

depends on the dedication and support of twins like Margaret and Kathleen, as their data provides an invaluable window into changes in our health and well-being over time. We estimate that it has cost nearly £10,000 over this time to process and analyse their samples, questionnaires and conduct the research visits. This shows just how valuable twins like Margaret and Kathleen are to the research programme. Professor Tim Spector enjoyed meeting them and presented them with flowers and a card.

"We felt on top of the world after our visit to the Department and will not forget it for the rest of our lives. We had a wonderful time and loved talking to Professor Spector. Taking part in research has greatly benefited us as well as the research, because the tests give you peace of mind that you have had a thorough health check. In fact it was the DEXA scan that alerted us that we have osteoporosis and we have been on medication for it ever since which has really helped".
Margaret and Kathleen

WINNER!

Every-one who comes in for a twin visit is automatically entered into an iPad mini (or equivalent voucher) prize draw which takes place twice a year. Our latest winner, Jocelyn was excited to get the good news. In her words "I am delighted to have won. I don't remember entering the draw and was surprised when I first got the call as I never win anything. I don't feel the need for any incentive to take part in twin research but it was a very welcome bonus."

Anxiety

Anxiety is a subjectively generalized restlessness

DTR RESEARCHERS DISCOVER A STRONG GENETIC LINK TO ANXIETY

Latest research findings using the data of 730 twins by DTR researchers Dr Matthew Davies and Serena Verdi revealed new genetic factors associated with generalised anxiety disorder. They found that just under half of the cause of anxiety in a population is due to our genes. This may help to explain why anxiety can run in families and proves that there is a biological basis for anxiety. These genetic discoveries are an important breakthrough in helping to understand the cause of anxiety, and will help in the search for drugs that have the potential to help millions of people.

PRESTIGIOUS PRIZE AWARDED TO DTR RESEARCHER

Congratulations to the DTR team led by Dr Frances Williams on winning the 2015 International Society for the Study of the Lumbar Spine prize in Clinical Studies. The photograph shows Dr Williams and two collaborators receiving the award for research that used twin data on 850 twins from questionnaires and twin visits dating back to 1996. The researchers showed that specific changes in the vertebral endplate (as seen on spine MRI) are related to self-reported episodes of severe low back pain. The work will lead to a greater understanding of the mechanisms of spine degeneration and their relationship with episodes of low back pain. This work is particularly important because back pain is so common, with one in three of us affected in any given year. Research into the understanding of the cause of back pain and what makes some people susceptible could help doctors treat back pain as early as possible in its course thus preventing further pain and disability.



COLONOSCOPY STUDY

As a continuation of our work on gut bacteria (microbiome), we are currently recruiting eligible twins to invite them to St Thomas' for a colonoscopy (BUPA average cost equivalent £2350) in order to learn more about how our gut bacteria influence our health. Our research has already shown that gut bacteria is affected by our weight, the ageing process, allergies and medication intake, as well as other factors but the good news is that we can alter our gut microbiome through diet, and medication. Since every one of us, including identical twins, has our own individual microbiome signature, this study will help us tailor future treatment plans unique to each individual.

Introducing Gabriela, our Biobank Laboratory Manager

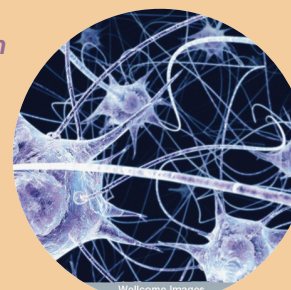
We would like to introduce an important member of our staff, Gabriela Surdulescu, our Biobank Laboratory Manager. Gabriela is in charge of the management and custodianship of all the samples provided by our twins, ensuring that ethical and regulatory standards such as confidentiality are applied at all times. She has been a key member of the Department of Twin Research since its inception in 1992 and remembers extracting the first ever DNA samples! Over the last 24 years she has processed, together with her team, over 500,000 samples stored in over 30 industrial scale secured freezers. Analysis of these samples has resulted in over 700 scientific papers and many important discoveries. She is very excited about expanding our storage facilities for our ever growing microbiome research. Since 2010 her team have stored over 3500 flora stool samples which her team will soon be processing further. In Gabriela's words "Thank you to all the twins who have donated blood, biopsies, urine, saliva and now stools; without their commitment and willingness to donate such a variety of samples we couldn't do our research." Thank you Gabriela! We also couldn't do it without you!



TWINSUK LEADS THE WAY IN ALZHEIMER'S PREVENTION AND AGEING RESEARCH

Dr Claire Steves, senior lecturer at the Department of Twin Research, recently published twin research on ageing that was reported world-wide and was covered widely throughout the British press. The researchers looked at over 1000 proteins in the blood of 100 sets of healthy twins and found that decreasing amounts of a protein called MAPKAP5 over a ten year period was associated with a decline in cognitive ability. Identifying blood markers such as MAPKAP5, which may indicate a person's future risk of Alzheimer's disease, could lead to early identification and prevention of Alzheimer's disease.

Dr Claire Steves said "We're optimistic that our research has the potential to benefit the lives of those who don't currently have Alzheimer's, but are at risk of developing the disease... We are hugely indebted to the twins for giving us their time and effort with these cognitive tests. We are continuing to follow-up both memory ability and cognitive testing in members of TwinsUK, which will be important in confirming and translating the science into benefits for older adults."



In related ageing research, Dr Steves has also published her findings that muscle fitness, as measured by leg strength, is strongly associated with an improved rate of ageing in the brain. She studied a sample of 324 healthy female twins from the TwinsUK volunteer registry over a ten-year period from 1999, measuring various health and lifestyle predictors. These findings suggest that simple interventions, such as increased levels of walking to improve leg power may have an impact on healthy cognitive ageing.

Look out for our next major research health questionnaire which we will be sending out to you at the end of the year. As mentioned in our previous newsletter, we are sending you longer questionnaires, but less often. We appreciate you completing the questionnaires as they are the source of much of the data that we use to publish many of the important findings.



Read more about our findings at www.twinsuk.ac.uk/general/

TWINSUK DISCOVERY: More than 11 moles on your arm could indicate higher risk of melanoma

Using data from members of TwinsUK, our researchers have discovered a new method that could be used by GPs to determine cancer risk by quickly guessing the number of moles on the entire body by counting the number found on a smaller 'proxy' body area, such as an arm. Between 1995 and 2003, 3594 twins underwent a skin examination and took part in this research.



HIGH PROTEIN FOODS BOOST CARDIOVASCULAR HEALTH

Our latest research in collaboration with the University of East Anglia shows that a diet high in proteins is as beneficial as exercise for our cardiovascular health. The researchers analysed diet and clinical measures from 2000 members of TwinsUK and found that high levels of amino acids have a positive effect on blood pressure and arterial stiffness.



TWINSUK CONTRIBUTES TO THE DISCOVERY OF IMPORTANT OSTEOPOROSIS GENE

Using the genetic data of 10,000 volunteers taking part in the UK10K project, which also included twin data from TwinsUK, researchers discovered a new genetic cause of osteoporosis. The research team was led by Dr. Brent Richards from Montreal's Jewish General Hospital, who is also an honorary Senior Lecturer at the DTR. The team discovered that a genetic variant near the gene EN1 has the strongest influence on bone mineral density and fractures ever discovered. The findings were published in the prestigious journal Nature. Osteoporosis is a common disease that can lead to fractures in between one-third and one-half of all women over the course of their lives. Because osteoporosis becomes more severe with age, it is becoming more prevalent with the overall aging of the population. There are currently few safe and effective treatments for osteoporosis, and no curative therapies available. In Dr Richard's words "EN1 has never before been linked to osteoporosis, so this opens up a brand new pathway to pursue in developing drugs to prevent the disease."

