KING'S College LONDON
University of London

Department of Twin Research & Genetic Epidemiology (DTR)

TwinsUK *newsletter*

Autumn 2014

Welcome to our 2014 newsletter

2013 was a year of celebration as we marked our 21st anniversary. This year is exciting in a different way, and we have already published over 50 papers in world class scientific journals with research about a 'carb-digesting gene' hitting the headlines in April (see 'Obesity study'). We have received new funding towards pain and our government-funded bioresource studies. Thank you to those 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,

Tim Spector

Bone density scan

You may have had a bone mineral density scan at a visit (called a DXA scan) and have received useful results. Our research has shown that, in the future, DXA scans (which have no side effects and are completely safe) may be used as an alternative to radiation-based scans to detect hardening of the arteries – an important warning sign for heart disease.

Fat biopsy

Thank you to those of you who had a small muscle/fat biopsy. Our recent results, using 856 twins, show that our genes switch on and off through our lives, but this process changes as we age, especially in the skin. Understanding which genes switch on and off as we get older is vital to discovering the mechanisms of healthy ageing so that we can encourage more people to take control of their health as they age.

Research Findings 2013-14

Below you will find a summary of some of our latest research findings and you will be able to see how your questionnaires and visits have translated into valuable scientific and medical findings. For more detailed information, please visit www.twinsuk.ac.uk/scientific-publications/

Obesity study

We always measure height and weight at twin visits and also take blood for DNA and biochemical markers. Using this information we have discovered that obesity in some people is related to the number of copies of a gene coding for a carb-digesting enzyme called 'Amylase'. The findings, published in Nature Genetics, show for the first time that the way our bodies digest carbs varies widely between us due to our genes and suggests that personalised dietary advice based on an individual's DNA may be the way forward in the fight against obesity.

Pain study

Many thanks to those of you who completed our pain questionnaires and patiently endured our heat pain test. Well it was worth the pain as we have recently published four papers on pain. DTR scientists compared differences in how our genes function in identical twins where one was really sensitive to pain and the other, insensitive. The researchers discovered that the pain gene, TRPA1 is controlled by epigenetics – which causes genes to be switched on or off in response to environmental factors. These results may provide fruitful new targets in pain management. We also found that people who have dry eye disease (with sore and gritty-feeling eyes) are more sensitive to pain, showing that common health conditions may be more burdensome if we are sensitive to pain. And finally, a study of more than 8,000 of you revealed that chronic pain syndromes - irritable bowel syndrome, musculoskeletal pain, pelvic pain and dry eye disease share a genetic element and that chronic pain may be heritable within families. It is thought that in these cases, the nervous system is sending pain signals to the brain without an obvious physical reason. The main investigator, Dr Frances Williams said

"With further research, these findings could lead to therapies which may change the lives of those suffering with chronic pain."

Read more about this research at: www.bbc.co.uk/news/health-27482574

Brain function studies

Many of you may remember doing puzzles and mental challenges on a computer at your visit. Using data on 300 people followed over ten years, we have discovered that genetic factors account for almost half of the change in brain function over time showing that normal cognitive ageing has a considerable genetic component.

TwinsUK in exciting merger with NIHR BioResource

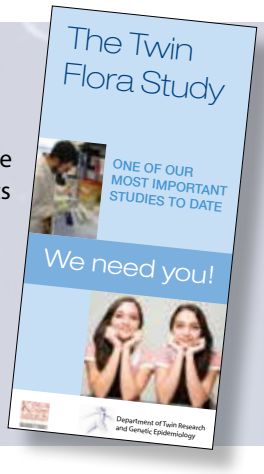
Two years ago, the DTR was delighted to be given the opportunity to integrate our TwinsUK registry into the national BioResource, a government initiative funded by the National Institute for Health Research (NIHR).

The NIHR BioResource has successfully brought together the efforts of excellent Biomedical Research Centres (BRC) across the UK. We are lucky that we have a BRC on our door-step, and one that shares our own vision and goals. The NIHR BRC at Guy's and St Thomas' NHS Foundation Trust and KCL is dedicated to 'translating scientific discoveries into improvements in treatment which will benefit patients at the earliest opportunity' - and our research at the DTR delivers the first stage of this goal through the discovery of important clinical findings.

Since we joined forces over two years ago, over 3000 of you have been for a BRC/TwinsUK visit that has hugely benefited both our own research programme and that of the NIHR, giving you more exciting opportunities than ever to take part in cutting-edge and meaningful research. The current research aims to understand better how our genes interact with the environment resulting in disease, and to develop new drugs and treatments. In the future we may also be able to offer you research opportunities at your local BRC which may benefit those of you who live further away from London. We may also invite you to do follow-up BRC studies to further the research. Further information on this initiative can be found via the website www.bioresource.nihr.ac.uk/about-us/about-the-bioresource/

Spotlight on our ongoing flora gut study

Over a thousand of you have kindly donated a stool sample; not your average donation, we appreciate, but thanks to you, we are learning just how much the bacteria in our gut affect our health. Even some DTR staff have donated to the research effort! We have discovered that there are very big differences in the types and amounts of bacteria we have in our guts and that both identical and non-identical twin pairs have about 50% of their bacterial groups in common. Other research has shown that the strongest 'inheritance' of bacterial groups is from mother to child. We have also found that the range of bacterial groups in TwinsUK members is similar to other European populations – much less diverse than people from Africa. Our next job is to learn which combinations of bacterial groups are the best and worst for health. It is exciting to work on a research project which could have very positive health outcomes, as one day dietary advice and antibiotic therapy could allow us to manipulate our healthy bacteria to our best advantage.



New format questionnaire

Our annual questionnaire that you receive by email or post is a critical source of valuable clinical information that forms the basis of much of our research. This year, we are changing the format of our annual questionnaire in order to update our database and gather as much important clinical information from as many of you as possible. Everyone will be receiving a longer questionnaire than normal, containing questions about the most important clinical and health care topics related to our latest research and also questions about diet. Although it will take a while longer to complete the questionnaire, we are hoping that the large number of topics covered will help us discover even more about the process of healthy ageing and disease. Thank you in advance for your help with this.

Searching for the secret of healthy ageing

Some 85 year olds are bright as buttons, fit as fiddles and as inspirational as Olympians. Why isn't everybody like that at 85, and what can we do now to keep ourselves alert, fit and independent as we age? We are at the start of a new and fascinating study that aims to discover telltale indicators, years in advance, of fitness and frailty. To do this study, we will be using all the clinical and lifestyle information we have collected (and continue to collect) on thousands of twins who have completed questionnaires and attended visits over the years, and will be looking for subtle differences in lifestyle, activity and physiology which could predict fitness in later life.

This important study could impact all our lives through clinically proven preventative medicine and lifestyle advice. You can learn more about ageing research at the DTR, led by Dr Claire Steves, by listening to her talk at www.tedxkingscollegelondon.com/claire-steves/

Lone twins

We have many dedicated twins who have taken part in our research who are 'lone twins' – either they are estranged from their twin, or their twin has passed away. These twins still come for visits and are a valuable contribution to the research as we use the results of ALL twins in our data analysis. If you are a lone twin, and would like to arrange to come in for a visit, please call 0207 188 5555 or email twinsuk@kcl.ac.uk

We are very grateful to Janet Baird for allowing us to interview her about being a lone twin.

What was your relationship with your twin? *We were very close. Margaret and I lived together until she passed away when we were 51.*

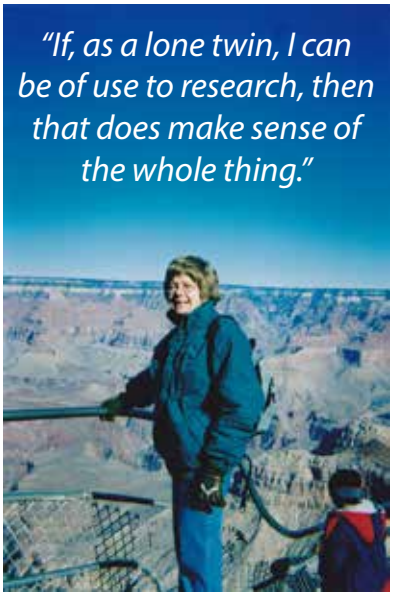
How did you cope with the loss of your twin? *Initially not well. It was a huge shock. I did all the usual lone twin things of trying to find a substitute twin - not a good idea. After ten years I am more resigned to my loss but I miss her every day.*

Do you have any suggestions to help people going through the loss of a twin? *I think the best way is to get in touch with other lone twins. Friends, relatives and counsellors will try to help you but it's difficult for them to really understand the magnitude of twin loss. If you've been close to your twin like I was, it's half your life gone. More information about support for lone twins can be found on www.lonetwinnetwork.org.uk*

Are you involved with a lone twin group? *I run my own lone twin group in Yorkshire. We meet three times a year and share how we feel and also keep in touch by email. I am not a counsellor or therapist - just a lone twin who understands how it feels. I also work for Lone Twin Network as a committee member.*

In what way is your twin still with you today? *My twin is with me and within me. I can sense my twin is around, even hear her voice, her chuckle. As Joan Woodward, the founder of the 'Lone Twin Network' said to me. "We don't move on, we move forward, with our twins".*

Why is it still important for you to volunteer as a lone twin for TwinsUK? *Margaret and I used to take part in research for TwinsUK. We travelled down to London from Yorkshire and we felt so good about doing that. We both had complex health problems but it was great to feel we could contribute. If, as a lone twin I can be of use to research, then that does make sense of the whole thing. I don't want to be a lone twin, but if my experience of being a twin can help just one other person, then it is worthwhile...*



Twin organ donation saves lives

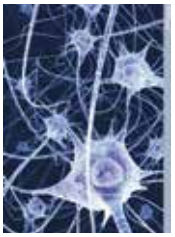
Twins are in a unique position both during their lives and after, to contribute to medical science and to save lives through either organ or brain donation. Here are two ways that can make a big difference.

Identical twin donates kidney

Identical twins and members of TwinsUK, Roger and Andrew Corke became aware that over 7000 patients are awaiting a transplant in the UK, most of whom need a new kidney. They also learnt how safe kidney donation is and realised that, being identical twins, if one of them donated a kidney, they would still have a genetically identical donor on hand if need be.

In September 2013, Roger donated one of his kidneys to a stranger as he was the one who lived closest to a transplant centre. **www.giveakidney.org** told them that they are the first identical twins to donate a kidney to a stranger in this manner. Roger and Andrew believe that if just a small percentage of identical twin pairs in Britain donated a kidney between them, hundreds of lives could be saved each year.

Brain donation - a gift of hope



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Many thanks to all of you who have registered with the twin brain donor research programme based at the MRC London Neurodegenerative Diseases Brain Bank, Kings College London. A commitment from twins to donate their brain after death is particularly valuable since the comparison of brain tissue of identical and non-identical twin pairs can provide an unparalleled insight into the working and ageing of the human brain. Brain donation provides an essential resource for researchers to understand the cause of common brain diseases such as dementia, psychiatric disorders and movement disorders and to develop future treatments.

For more information please contact the Brain Bank team on 020 7848 0290 or for more information via the internet, search for "MRC London Neurodegenerative Diseases Brain Bank".

What's our name?

We are fortunate to have a lot of names and associations – but even we get confused sometimes, so hopefully this will make it clearer…

TwinsUK – the name of the twin registry – all of YOU!

Department of Twin Research (DTR)– the name of the Department, within the University of **King's College London (KCL)**. The DTR studies the twin data from TwinsUK to discover the causes of complex disease and ageing. The DTR/TwinsUK are both located at St Thomas Hospital, but is not run by the hospital.

Twin visit helps twin ward off fractures

We are always grateful for the effort many of you go to when you come for a visit. We are very happy to hear when we have also helped you.

Gail has volunteered as a member of TwinsUK for 17 years. In 2000 she had a bone density scan of her hip and spine during a research visit at St Thomas'. She learnt from the results that she has osteoporosis and has been on medication ever since. She was also advised to do weight bearing activities and increase her calcium intake. Gail believes that since the NHS does not routinely offer bone tests, if she hadn't have come for a visit and made the discovery about her osteoporosis, then her condition would have worsened, possibly resulting in fractures.

Our research – spreading the word

We have had a number of amazing opportunities over the last year to engage with the public about our research, allowing everyone access to science and a greater understanding of the importance of healthy ageing.

Our engagement events included a 21st Anniversary party which received world-wide media attention, an interactive twin research exhibition at the Science Museum's Late Bio-revolution evening attended by 6,900 people and a TedxKingsCollegeLondon event titled "Beyond the genes: Identity, health, culture".

Visit our regularly updated interactive web-site (**www.twinsuk.ac.uk**), 'like us' on facebook, follow us on twitter and make sure we have your latest email address so that you can be one of the first to learn about exciting DTR news, events, press releases, media appearances and public events.

facebook.com/twinsuk

twitter@TwinsUKres

youtube.com/user/DeptTwinResearch

Collaborator studies

Please see below some studies from fellow scientists on hair loss and telepathy. **Please note that the DTR is not responsible for the studies. If you are interested, please contact them directly.**

Have you ever been diagnosed with scarring alopecia or lichen planus or sclerosus, or have you excessive hair shedding?

If you answered 'yes' to the question above you may be in a position to help researchers studying distressing inflammatory skin conditions and scarring alopecias, for which current treatments are ineffective. The research is led by Dr Christos Tziotzios and Prof John McGrath, at the St John's Institute of Dermatology, King's College London. If you are interested in taking part please email christos.tziotzios@kcl.ac.uk
The study will involve a brief (approximately 7-minute) telephone questionnaire and possibly a research visit for clinical assessment and advice, if needed.

Are you interested in taking part in telepathy and attachment research?

Some of you completed the 'Exceptional Experiences Questionnaire' at the 2009 and 2013 twin days that examined the connection between exceptional experiences (including telepathy-like experiences, shared dreams and remarkable coincidences) and the attachment and emotional bond between twins. A significant relationship was found to occur between reporting a strong attachment and having exceptional experiences. The majority of these experiences were reported to have occurred in a waking state. Almost half of twins who reported telepathy said that it occurred during a time of pain, illness or injury. If you and your twin are interested in taking part in further telepathy and twin research which will take place at the University of Greenwich under Dr David Luke and Dr Claire Monks, please email Göran Brusewitz at goran.brusewitz@bredband.net

If you haven't been in for a study for over 2 years and would like to come for a visit, and/or would like to take part in our latest postal studies including the flora gut study please call 0207 188 5555 or email twinsuk@kcl.ac.uk

CHANGE OF DETAILS?
To update your details, including your latest email address, please email us at: twinsuk@kcl.ac.uk or call us on 0207 188 5555

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TwinsUK Newsletter Editor: Juliette Harris, PhD. | ©2014 Department of Twin Research | Design and artwork: Barbara Pilgrim of www.factorestudio.com

Major Research Sponsors: NHS National Institute for Health Research; erc 5 years; wellcome trust; European Commission