Scientists seeking Tasmanians for world’s largest anorexia nervosa genetics study

Anorexia nervosa four-to-six times more common among families: new research

Australian scientists are calling for volunteers who are living with, or have recovered from anorexia nervosa, to enrol in the world’s largest and most rigorous genetic investigation into the illness.

The Anorexia Nervosa Genetics Initiative (ANGI) aims to identify the genes that play a role in causing the serious and potentially life-threatening illness, affecting an estimated 1,200 Tasmanians.1,2

According to lead Australian study investigator, Head of the Genetic Epidemiology group, QIMR Berghofer Medical Research Institute, Professor Nicholas Martin, PhD, Brisbane, researchers are seeking volunteers to shed light on identifying the genes that predispose people to anorexia nervosa.

“New research reveals people living with anorexia nervosa have four-times more direct relatives with anorexia nervosa than those who have never had the illness.” In particular, life-time anorexia nervosa is six times more common in mothers, four times more common in siblings and five times more common in the offspring of people living with the illness.3

“Results of this research underscore the critical importance of identifying genes that lead to the pattern that we have seen in families,” Prof Martin said.

“For decades studies have shown a strong genetic link to the illness. However, we’ve been unable to pinpoint particular genes or determine where the genetic link lies, to date,” said visiting ANGI lead investigator, Distinguished Professor of Eating Disorders, Department of Psychiatry, School of Medicine, University of North Carolina, USA, Professor Cynthia Bulik.

“As such, we urge any Tasmanian who is living with, or has lived with anorexia nervosa, to join our very important scientific journey of discovery,” Prof Bulik said.

“Participating in ANGI is easy and free. Volunteers simply complete a 10-minute online, confidential survey and roll up their sleeves to provide a very small blood sample.

“It costs nothing apart from a little time, but could make a genuine contribution to solving this devastating illness,” said Prof Bulik.

Volunteers can be male or female of any age (children require parental consent) who:
- Currently have anorexia nervosa; or
- Have had anorexia nervosa at some stage in their lives.

To learn more, or to register for the study:
- Visit angi.qimr.edu.au
- Email angi@qimrberghofer.edu.au
- Freecall ANGI on 1800 257 179.

“Given recent advances in molecular sequencing techniques, we are hoping to identify the specific genes that may be responsible for anorexia nervosa and thereby pave the way for new treatments that specifically target the illness,” Prof Martin said.

ANGI researchers will analyse DNA samples through a process known as ‘genome-wide association’, comparing the DNA of people who have never had an eating disorder to those who currently have, or have had, anorexia nervosa. Comparative analysis not only serves to identify and discover genes that predispose people to eating disorders, but to also pinpoint genes responsible for depression, anxiety, alcoholism and other common mental health illnesses.4

ANGI is being conducted in four centres worldwide including a combined Australia and New Zealand site, Denmark, Sweden and the US. Australia plans to contribute more than a quarter of the total 13,000 DNA samples required for the initiative.

“We are aiming to recruit 2,200 Australian blood donors within the next two years and may even increase this number to 5,000 by 2017 depending on community support for this groundbreaking research initiative,” said Prof Martin.

“While identifying the genes associated with anorexia nervosa will not imply people with such genetic background will develop anorexia nervosa during their lifetime, it will help healthcare professionals to identify those who may be vulnerable to the disorder, and to manage their treatment accordingly.” Prof Martin said.
Dr Fiona Wagg, Child & Adolescent Psychiatrist, Mental Health Services, Royal Hobart Hospital, Hobart, says encouraging people who have, or have had, anorexia nervosa to participate in the initiative will help transform current knowledge of anorexia nervosa causes.

“ANGI will enable us to work towards a greater understanding of, and ultimately a cure, for the illness.

“We know the causes of anorexia nervosa are varied and complex and include a combination of environmental, social and cultural factors. However, genetic predisposition is a known cause and should be a key area of focus,” said Dr Wagg.

Anorexia nervosa is characterised by an obsessive desire to lose weight through restricting calorie intake and is associated with low body weight, difficulty maintaining a healthy body weight, fear of weight gain and extreme focus on weight and shape.

The illness afflicts people from all age groups, socio-economic and cultural backgrounds. While anorexia nervosa typically starts, and is more common among adolescent girls, affecting four-in-every-100, the most serious forms of the illness occur in adults aged 25-to-45 years.

Working professional, Maddy, 20, Hobart, battled anorexia nervosa during her early teens and is now fully recovered and working for a not-for-profit organisation specialising in aged care.

“It’s a mental illness with physical complications. Many people mistakenly assume once you are physically ‘healthy’, everything is back to normal.

“Anorexia nervosa held me back from doing a lot. I missed out on being a teenager due to lack of energy or undergoing treatment,” said Maddy.

Maddy lived with anorexia nervosa for a year. During this period her friends found her illness confronting and hard to understand, leaving her isolated. For Maddy, the recovery process was a long road. While improving physically after only 18 months, her mental recovery took five years after initially commencing treatment.

“Learning to accept myself for who I am and developing self-worth was extremely hard work,” Maddy said.

“An eating disorder isn’t something you can fight on your own. You need support, assistance and guidance, which unfortunately, so many of us refuse.

“If you have the personality traits and genetics and are put in the wrong environment, it can blow up, “said Maddy.

While full recovery of anorexia nervosa is possible, particularly with early treatment and the support of a multidisciplinary healthcare team, ANGI researchers hope their research will lead to a better understanding of the condition, enabling a more successful treatment process.

Blood donations will be used to extract DNA which will be bio-banked for immediate and future genetic analysis under strict confidentiality and within Commonwealth privacy and National Health and Medical Research Council (NHMRC) guidelines.

Blood donation involves attending any local pathology clinic with a kit mailed to participants from QIMR Berghofer containing blood collection and information pack, participant instructions, blood collector instructions, blood collection tubes and a reply-paid, pre-addressed courier bag.

For more information, or to register for ANGI, visit angi.qimr.edu.au.

About the QIMR Berghofer Medical Research Institute (QIMR Berghofer)

QIMR Berghofer is a world-leading translational research institute specialising in cancer, infectious diseases, mental health and a range of complex diseases. Working in close collaboration with clinicians and other research institutes, QIMR Berghofer aims to improve health by developing new diagnostics, better treatments and prevention strategies. For more information on QIMR, head to www.qimr.edu.au.

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If you, or a loved one is currently living with anorexia nervosa, The Butterfly Foundation’s ED HOPE service offers support via phone (1800 33 4673), email (support@thebutterflyfoundation.org.au) or live chat (www.thebutterflyfoundation.org.au).

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