

AUS researchers seeking 3,500+ volunteers for world's largest eating disorders genetics investigation

Study to pinpoint genes influencing risk of developing eating disorders

Researchers are seeking Victorian volunteers with first-hand experience of eating disorders to enrol in the local arm of the world's largest ever genetic investigation into the complex, devastating illnesses.

The ground-breaking Eating Disorders Genetics Initiative (EDGI) aims to identify hundreds of genes that influence a person's risk of developing anorexia nervosa, bulimia nervosa and binge-eating disorder, to improve treatment, and ultimately, save lives.

According to an EDGI investigator article just published in *MJA Insight*,¹ EDGI will further the significant advances made in a recent, international collaborative study – Anorexia Nervosa Genetics Initiative (ANGI) – in order to revolutionise future research into the causes, treatment and prevention of eating disorders.

"Identifying the genes that predispose individuals to the development of an eating disorder is like assembling a jigsaw puzzle. The more pieces we have on the table, the clearer the biological picture of the underlying causes of the disorder, and the better the chance of developing new and improved, personalised interventions and treatments," said article co-author, EDGI Principal Investigator, Distinguished Professor of Eating Disorders, Department of Psychiatry, School of Medicine, University of North Carolina, Professor Cynthia Bulik, USA.

"Genetically, our preliminary ANGI research, which compared 17,000 participants with more than 55,000 controls from 17 countries, revealed both psychiatric and metabolic origins to anorexia nervosa, explaining why people living with the disorder struggle to gain weight, despite their best efforts. The study also identified eight genetic variants significantly associated with anorexia nervosa.²

"Our new study, EDGI, offers us a unique opportunity to further investigate the complex interplay of genetic and environmental factors that contribute to eating disorders, in order to improve treatments, and save lives," Prof Bulik said.

Eating disorders are complex mental illnesses that for some, can lead to severe and permanent physical complications, and even death.³ While various studies have explored one's genetic predisposition to developing an eating disorder, only a handful of the responsible genes have been identified to date, leaving many more to be found.

Australian Lead Investigator, Geneticist and Head of the Genetic Epidemiology Research Group, QIMR Berghofer Medical Research Institute, Professor Nick Martin, Brisbane, is seeking more than 3,500 Australians to volunteer for EDGI.

"With approximately 266,000 Victorians thought to be living with an eating disorder, we are looking for any Australians, aged 13 and over, with first-hand experience of an eating disorder, to volunteer for this important genetics study."^{4,5}

Volunteers need to be aged 13 years or over* and have currently, or at any point in their lives experienced, anorexia nervosa, bulimia nervosa or binge eating disorder.

To learn more, or to register for the study:

- Visit www.edgi.org.au
- Email edgi@qimrberghofer.edu.au

"Decades of family and twin studies have confirmed that eating disorders run in families due to genetic factors,"⁶ said Prof Martin.

"Breakthroughs made possible with genome-wide association studies (GWAS), such as EDGI, use postage stamp-sized 'genetic chips' to allow analysis of up to one million genetic markers.⁷ These markers investigate single letter variations in the DNA (A,C,G,T – the building blocks of DNA) across all 23 chromosomes.⁸

more#

"Each of these variants can then be tested statistically for association with eating disorders, by comparing the genomes of large numbers of individuals with eating disorders to large numbers of individuals without the diseases,"^{9,10} Prof Martin said.

"Analysing the DNA from study saliva samples will allow us to pinpoint specific genes associated with eating disorders, which will help us to determine why some people experience eating disorders, and why some people living with eating disorders respond to certain treatments, while others do not.

"Comparing the saliva samples of EDGI participants to samples collected for other disorders, will also help us to understand the common conditions co-occurring with eating disorders, including obsessive-compulsive disorder, depression, anxiety, substance abuse disorders and personality disorders,"^{9,11,12} said Prof Martin.

According to the founder of the eating disorders coaching service, *Uncovery*, and Carolyn Costin Institute-certified Eating Disorder Recovery Coach, Olivia Soha, Melbourne, eating disorders are not a choice, but rather, serious illnesses¹³ that can cause significant distress, and affect the lives of individuals, their partners, families, carers and friends.¹⁴ Concerningly, eating disorders have one of the highest mortality rates of any mental illness.^{11,15,16}

"For far too long, eating disorders have been perceived as illnesses that pivot around the external; a physical ideal and pursuit of beauty or body image. In reality however, eating disorders are mental illnesses driven by what is going on in the mind, and involve a complex interplay of environmental and genetic factors."

Mum and early childhood teacher, Amy, 33, Melbourne, waged a decade-long-battle with anorexia nervosa. Amy believes her sensitive personality, being teased at school, hitting puberty early, and her peers' subsequent, positive reinforcement of her initial weight loss, collectively triggered her eating disorder and another mental illness.

"There was a constant voice in my head telling me I was fat, worthless and always wrong," Amy said.

After her diagnosis with anorexia nervosa at 15 years of age, Amy was enrolled in an outpatient adolescent health facility in Melbourne. Yet despite the treatment she received, and invaluable support from her family and friends, Amy nonetheless, continued to lose weight while also fighting clinical depression.

"I was eventually admitted to hospital because my body was giving up on me. My kidneys were starting to fail, I was jaundiced, had significant muscle deterioration, and was at risk of heart failure.

"We need to know more about eating disorders and the predisposing factors. We need better treatments and better recovery rates, which is why I'm participating in EDGI," said Amy.

"I'm confident EDGI will help to pave the way toward improved diagnosis, management and treatment for those living with eating disorders."

Should you suspect that you, or a loved one, may be living with an eating disorder, speak to your local healthcare practitioner without delay, or head to www.insideoutinstitute.org.au to complete their screener and assessment, and to access more information and professional support.

Australian professional patient support services offering 24/7 helpline services include:

- **Beyond Blue: 1300 22 4636**
- **LifeLine: 13 11 14**
- **Men's Line Australia: 1300 78 99 78**
- **Kids Help Line: 1800 55 1800.**

**Children aged 13 to 17 years wishing to volunteer for the study must be supervised by a guardian.*
ends#

Issued by VIVA! Communications on behalf of QIMR Berghofer.

MEDIA CONTACTS:

Kirsten Bruce & Mel Kheradi, VIVA! Communications
T 0401 717 566 | 0421 551 257 | 02 9968 3741/1604
E kirstenbruce@vivacomcommunications.com.au
mel@vivacomcommunications.com.au

MEDIA KIT:

Digital media kit – www.edgimediakit.org.au

BROADCAST VISION:

Available for download – <https://vimeo.com/458058145/bd7600402d>

JOIN THE CONVERSATION:

Like us on Facebook: www.facebook.com/EDGI.AUS

Follow us on Twitter: www.twitter.com/EDGI_AUS

REFERENCES

1. Bulik, C., Martin, N. *Finding pieces of the puzzle: Australia and New Zealand anchoring the Eating Disorders Genetics Initiative (EDGI)* 2020.
2. Watson, H.J., et al., *Genome-wide association study identifies eight risk loci and implicates metabo-psychiatric origins for anorexia nervosa*. *Nature Genetics*, 2019. 51(8): p. 1207-1214.
3. National Eating Disorders Collaboration. *What is an eating disorder?* . [cited October 2019]; Available from: <https://www.nedc.com.au/eating-disorders/eating-disorders-explained/something/whats-an-eating-disorder/>.
4. Butterfly Foundation for Eating Disorders. *Paying the price - The economic and social impact of eating disorders in Australia*. 2012 [cited Dec, 2019]; Available from: <https://thebutterflyfoundation.org.au/assets/Uploads/Advocacy/Butterfly-Report-PayingthePrice.pdf>.
5. Australian Bureau of Statistics. *Australian Demographic Statistics*, Dec 2019. 2019 [cited September, 2020]; Available from: <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/3101.0Main%20Features3Dec%202019?opendocument&tabname=Summary&prodno=3101.0&issue=Dec%202019&num=&view=>.
6. Wade, T.D., et al., *Prevalence and long-term course of lifetime eating disorders in an adult Australian twin cohort*. *Aust N Z J Psychiatry*, 2006. 40(2): p. 121-8.
7. *Gene chips*, in *Rheumatology and Immunology Therapy*, J.D. Abbott, et al., Editors. 2004, Springer Berlin Heidelberg: Berlin, Heidelberg. p. 347-347.
8. National Institutes of Health (US); Biological Sciences Curriculum Study. *NIH Curriculum Supplement Series [Internet]*. Bethesda (MD): National Institutes of Health (US); 2007. *Understanding Human Genetic Variation*. 2007 [cited July 2020]; Available from: <https://www.ncbi.nlm.nih.gov/books/NBK20363/>.
9. Bulik, C.M., L. Blake, and J. Austin, *Genetics of Eating Disorders: What the Clinician Needs to Know*. *Psychiatr Clin North Am*, 2019. 42(1): p. 59-73.
10. Dunn, E.C., et al., *Genetic determinants of depression: recent findings and future directions*. *Harv Rev Psychiatry*, 2015. 23(1): p. 1-18.
11. **Ministry of Health**. *Future Directions for Eating Disorders Services in New Zealand*. 2008 [cited Dec, 2019]; Available from: <https://www.health.govt.nz/system/files/documents/publications/future-directions-eating-disorders-services-nz-v2.pdf>.
12. Jordan, J., et al., *Specific and nonspecific comorbidity in anorexia nervosa*. *International Journal of Eating Disorders*, 2008. 41(1): p. 47-56.
13. Walker, S. and C. Lloyd, *Barriers and attitudes health professionals working in eating disorders experience*. *International Journal of Therapy and Rehabilitation*, 2011. 18(7): p. 383-390.
14. NSW GOVERNMENT Health. *NSW Service Plan for People with Eating Disorders 2013-2018*. [cited DEC, 2019]; Available from: <https://www.health.nsw.gov.au/mentalhealth/resources/Publications/service-plan-eating-disorders-2013-2018.pdf>.
15. Smink, F.R.E., D. van Hoeken, and H.W. Hoek, *Epidemiology of eating disorders: incidence, prevalence and mortality rates*. *Current psychiatry reports*, 2012. 14(4): p. 406-414.
16. Fichter, M. and N. Quadflieg, *Mortality in eating disorders - Results of a large prospective clinical longitudinal study*. *The International journal of eating disorders*, 2016. 49.