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

Study to pinpoint genes influencing risk of developing eating disorders

New Zealand researchers are seeking volunteers with first-hand experience of an eating disorder 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 a co-authored EDGI Investigator article published today in the Royal New Zealand College of General Practitioner's (RNZCGP), *GP Pulse*, NZ volunteers stand to make an invaluable contribution to improving the lives of those living with eating disorders.

"Cracking the genetic code of eating disorders will open the floodgates to much-needed research and the development of new, and more effective, personalised treatments for these devastating illnesses," said article co-author, visiting EDGI Principal Investigator, Distinguished Professor of Eating Disorders, Department of Psychiatry, School of Medicine, University of North Carolina, Professor Cynthia Bulik, USA.

"Our preliminary research has shown that genetically, anorexia nervosa has both psychiatric and metabolic origins, which explains why people living with the disorder struggle to gain weight, despite their best efforts," said Prof Bulik.

"EDGI NZ 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."

Eating disorders are complex mental illnesses that for some, can lead to severe and permanent physical complications, and even death.[1] 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.

Psychologist, Senior Lecturer, University of Otago, and EDGI NZ Co-lead Investigator, Dr Jennifer Jordan, Christchurch is seeking more than 3,500 New Zealanders to participate in the important genetics study.

"We are looking for any New Zealander, aged 16 and over, with first-hand experience of an eating disorder, to volunteer for this important genetics study."

Volunteers need to be over 16 years of age 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.nz**
- **Email edgi@otago.ac.nz.**

"Analysing the DNA (genomes) 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," Dr Jordan said.

"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 depression, anxiety, obsessive-compulsive disorder, substance abuse disorders and personality disorders,"[2,3]

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EDGI follows the recent ground-breaking advances made through the collaborative Anorexia Nervosa Genetics Initiative (ANGI), in which 17,000 participants were compared to over 55,000 controls from 17 countries. Eight genetic variants significantly associated with anorexia nervosa were identified.[4]

Eating disorders are not a choice – they are serious illnesses[5] that can cause significant distress, and affect the lives of individuals, their partners, families, carers and friends.[6] Concerningly, eating disorders have one of the highest mortality rates of any mental illness.[1,7,8]

"At present, we don't fully understand why people succumb to an eating disorder. EDGI will help us to tease out the biological components that put people at risk of developing an eating disorder," said Genetics Researcher, University of Otago, and EDGI NZ Co-lead Investigator, Professor Martin Kennedy, Christchurch.

"Identifying the genes involved with eating disorders will provide us with a much better understanding of the biochemistry and the pathways that predispose people to developing anorexia nervosa, bulimia nervosa or binge eating disorder. If we can understand this, then we've got a very real chance of developing better, more appropriate treatments.

"Decades of family and twin studies have confirmed that eating disorders run in families due to genetic factors,"[9] Prof Kennedy said.

"Genome-wide association studies (GWAS) – the technology used to explore the genetics of these disorders – places markers across complete sets of DNA of those with the disorder, compared to unaffected controls, to identify specific differences in the genome that contribute to the risk of developing an eating disorder."

'Health navigator', Megan, 23, Christchurch, who helps people conquer medical and mental health challenges hindering them from returning to work or study, spent eight years in the grip of a devastating eating disorder.

After being diagnosed with anorexia nervosa at the age of 16, Megan's life soon spiralled out of control.

"It was like having both your best friend and your worst enemy's voices inside your head, all day, every day.

"The best friend "voice" was always there to support and accompany me, albeit supporting terrible tendencies and habits," said Megan.

"The worst enemy "voice" however, was abusive and derogatory, and said things to me that I would never utter, even to my worst enemy."

Eventually, armed with the invaluable guidance and support of her parents, psychologist, dietitians and nurses, Megan developed the necessary coping strategies and determination to escape "a very dark, lonely and unhealthy place".

Convinced of the genetic component to eating disorders, given four of her family members have wrestled with disordered eating, Megan has chosen to support the NZ arm of EDGI.

For Māori and Pacific communities who comprise approximately 16 per cent of our population,[10,11] data suggest eating disorders are at least as common among these populations, as the remainder of the population.[12] However, these communities are less likely to have contact with health services for mental health reasons, suggesting barriers to accessing crucial eating disorders health services.

If you, or a loved one is currently living with an eating disorder, contact Eating Disorders Association of NZ (EDANZ) for support on 0800 2 EDANZ or info@ed.org.nz.

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