

Lisa Curry AO leading national call for 4,000+ adult volunteers for world's largest genetics study on eating disorders

Decoding the genetics of eating disorders to identify risk & transform treatment

Triple Olympian Lisa Curry AO is fronting a national appeal today for 4,000+ adults with lived experience of an eating disorder to join the world's largest genetics investigation into the risk factors driving these complex illnesses.¹

The Eating Disorders Genetics Initiative 2 (EDGI2) aims to pinpoint the hundreds of genes influencing a person's risk of developing anorexia nervosa, bulimia nervosa, binge-eating disorder and Avoidant Restrictive Food Intake Disorder (ARFID), to improve treatment, and save lives.

Ms Curry's appeal for EDGI2 volunteers, in partnership with researchers, doctors and patients Australia-wide today, coincides with an article just published in [MJA Insight+](#), revealing how the complex interplay of genetic, environmental and psychological factors in eating disorders,² has hindered effective treatment breakthroughs.³

The Aussie sporting legend, mother-of-three, and champion for mental and physical wellness, is supporting EDGI2 due to the heartbreaking loss of her daughter Jaimi, 33, to long-term health challenges, including anorexia nervosa.

"Too little is known about eating disorders, which affect over a million Australians.⁴

"Eating disorders remain among the most stigmatised mental health conditions. This stigma often prevents people from seeking help, making things worse,"⁵ said Ms Curry.

"Individuals and families affected by eating disorders deserve answers, earlier intervention, and personalised treatments that work.

"EDGI2 unites global experts to unravel the complex genetic and environmental puzzle behind eating disorders," Ms Curry said.

"I urge every Australian aged 18+ with experience, past or present, of one of four eating disorders – anorexia nervosa, bulimia nervosa, binge-eating disorder or ARFID – to volunteer for this vital research.

"Head to edgi2.org.au or email edgi2@qimrb.edu.au to volunteer or learn more. Recruitment closes December 31, 2025," said Ms Curry.

According to Head of the Genetic Epidemiology Laboratory, QIMR Berghofer, and Lead Australian EDGI2 Investigator, Professor Nick Martin, Brisbane, this new study builds on the ground-breaking progress of the original EDGI investigation, and the collaborative Anorexia Nervosa Genetics Initiative (ANGI), which identified the first eight genes linked to anorexia nervosa, highlighting both psychiatric and metabolic causes of the illness.⁶

"This discovery was completely unexpected, and requires urgent replication and further study to fully understand the pathways leading to anorexia nervosa.

"That's why a larger sample size is crucial, which is the aim of EDGI2," said Prof Martin.

"While rigorous research shows genes account for more than half the risk of eating disorders,⁷ we still lack understanding and accurate tools to predict their progression, or response to treatment."

The world-leading geneticist explains EDGI2's strength will lie in its unprecedented scale and diverse, multi-country sample.

"Large-scale studies like EDGI and ANGI have demonstrated the genetic basis of eating disorders, and helped identify variations that can calculate an individual's genetic risk.⁸

"A larger, more diverse sample will enhance our understanding of genetic risks, vulnerabilities, and protective factors, leading to earlier, more personalised treatments, and better predictions of disease progression and future risk,"⁸ Prof Martin said.

"With the Aussie spirit of volunteering, I'm confident we'll reach our goal of 4,000+ EDGI2 participants."

Clinical Psychologist, Director, InsideOut Institute, and EDGI2 Australia Chief-Investigator, Prof Sarah Maguire OAM, Sydney, explains eating disorders can affect people of any age, weight, size, shape, cultural background, or identity, and significantly compromise quality of life.

"They impact the individual, and their family in just about every way possible – professionally, personally, emotionally and psychologically."⁹

"Eating disorders can also have serious medical consequences.^{10, 11} They have a strong link to depression, anxiety, obsessive-compulsive symptoms, social isolation, and sometimes, suicide,"^{1,12} said Prof Maguire.

"Their medical complications may include cognitive impairment, heart issues, growth retardation, and osteoporosis."^{10,11}

"The eating disorders mortality rate is significantly higher than other psychiatric conditions, mainly due to medical complications, and the rate of suicide,"¹³ Prof Maguire said.

"Importantly, eating disorders are treatable.¹⁴ Research advances like EDGI2, which enhance understanding of genetic and environmental factors, along with early detection and personalised treatment, are key to recovery and improved patient management."^{15,16}

Executive Director, Eating Disorders Families Australia (EDFA), and lived-experience carer, Jane Rowan, Brisbane, emphasises "eating disorders are not a choice – they are serious mental illnesses."¹⁷

"However, with early intervention and a comprehensive approach that addresses the physical, psychological, and social aspects of an eating disorder, recovery is possible for everyone, regardless of severity or stage of illness,"^{14,18} said Ms Rowan.

Ms Rowan is a strong advocate for EDGI2.

"EDGI2 represents hope – not just for better treatments, but for a deeper understanding of eating disorders.

"Ultimately, EDGI2 will give families the answers we've been seeking for so long, and will help them to feel seen and supported," Ms Rowan said.

Lived experience educator and dog lover, Shannon, 48, Perth, was diagnosed with anorexia nervosa and bulimia nervosa at 13 years of age. She was in and out of hospital with both disorders for more than three decades. Her above-average height for her age and the reproductive health issues she experienced during puberty, which required medication, contributed to weight gain, emotional distress, and feelings of shame, eventually leading to restrictive eating and binge-purge behaviours.

"I was taller than my peers, and people would say, 'You're a big girl.' They meant tall, but as a child, the word 'big' left little room for interpretation – and certainly not in a positive light," said Shannon.

Fluctuating between anorexia nervosa and bulimia nervosa, Shannon battled a relentless cycle of restriction, bingeing, purging, and laxative use that continued for decades.

"My symptoms included daily laxative abuse, bingeing, and purging, worsened by severe food restriction and nutrient deprivation. It did so much damage physically and mentally," Shannon said.

Shannon acknowledges a family history of disordered eating and possible eating disorders, suggesting a genetic link to her own experience.

"I believe an aunt had anorexia nervosa, and reflecting upon past behaviours, I've observed what I recognise as disordered eating, and possible undiagnosed eating disorders in several family members over the years."

Now nine years into her recovery, Shannon uses her lived experience with longstanding eating disorders and mental health challenges to work with her peers on supporting and improving systemic reform.

EDGI2 participation involves:

1. Providing informed consent and completing a short, 15–20 minute, online survey.
2. Following core survey completion, eligible participants will be asked to donate a saliva sample.
3. Researchers sending a saliva collection kit together with a pre-paid return envelope to selected participants.
4. EDGI2 researchers extracting DNA from saliva samples to identify specific genes associated with eating disorders.

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

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

- **Butterfly National Helpline: 1800 334 673**
- **Beyond Blue: 1300 22 4636**
- **Lifeline: 13 11 14**
- **Men's Line Australia: 1300 78 99 78**
- **Kids Help Line: 1800 55 1800**

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AVAILABLE FOR INTERVIEW

LISA CURRY AO

Lisa Curry AO has provided an extensive, pre-recorded VNR interview + supporting overlay, audio grabs & a piece-to-camera, all of which are available for download from our digital media kit: edgi2mediakit.org

EDGI2 AUSTRALIA INVESTIGATORS

Prof Nick Martin	Lead Investigator, Eating Disorders Genetics Initiative 2 (EDGI2) & Head, Genetic Epidemiology, QIMR Berghofer, BRISBANE
Prof Sarah Maguire OAM	Chief Investigator, EDGI2 Australian, Clinical Psychologist & Director, InsideOut Institute, SYDNEY

EDGI2 PRINCIPAL INVESTIGATOR – INTERNATIONAL

Prof Cynthia Bulik	Distinguished Professor of Eating Disorders; Founding Director, Centre of Excellence for Eating Disorders, University of North Carolina; Founder & Director, Centre for Eating Disorders Innovation at Karolinska Institute; & Principal Investigator, Eating Disorders Genetics Initiative 2 (EDGI2), NORTH CAROLINA, USA & SWEDEN
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OTHER EXPERTS

Annabel Johnston	Gut health dietitian and founder, Nutrition for Living, BRISBANE
Olivia Soha	Certified Eating Disorder Recovery Coach & Founder & Director of 'Uncovery' who lived with an eating disorder, MELBOURNE
Dr. June Alexander	Author, life-writing mentor, blogger, diarist & eating disorder advocate who lived with an eating disorder, GEELONG
Prof Tracey Wade	Matthew Flinders Distinguished Professor, College of Education, Psychology and Social, ADELAIDE
Prof Sarah Cohen-Woods	Professor of Psychology, Flinders University Institute for Mental Health and Wellbeing & Head of the Behavioural Genetic & Environmental Mechanisms Lab, Flinders University, ADELAIDE
Dr Bronwyn Raykos	Clinical psychologist, researcher & founder of Morgan Psychology, PERTH
Dr Tiegan Holtham	Clinical Psychologist, The Flourish Collective & Headspace, DARWIN
Natasha Berthold	PhD student, The University of Western Australia & The Perron Institute, & Visiting Scholar, University of North Carolina's Centre of Excellence for Eating Disorders, North Carolina, USA

PATIENT ADVOCACY GROUP REPRESENTATIVES

Jane Rowan	Executive Director, Eating Disorders Families Australia (EDFA) & lived experience eating disorder carer, BRISBANE
Mark & Gayle Forbes	Co-founders of mental health charity, endED, whose daughters have both lived with an eating disorder, SUNSHINE COAST
Don Irvine	Father who became an eating disorder advocate after his eldest daughter's decade-long battle with anorexia nervosa, PERTH

AUSTRALIANS WITH EATING DISORDER EXPERIENCE

Lexi, 36	Clinical nutritionist who endured more than 25 hospitalisations with anorexia nervosa over 18 years, BRISBANE
Emily, 22	Peer mental health support worker who wrestled with bulimia nervosa & binge eating disorder for over seven years, BRISBANE
Tayla, 25	Dietitian & former elite athlete who waged a silent battle with anorexia nervosa, SUNSHINE COAST
Rosiel, 34	PhD student, eating disorder lived experience consultant & identical twin who battled anorexia nervosa for 25+ years, SUNSHINE COAST
Hayley, 24	Student, artist & aspiring teacher who struggled with anorexia nervosa for nine years, GOLD COAST
Elise, 39	Breathwork & meditation facilitator, empowerment coach, cold immersion specialist who lived with anorexia nervosa for 23 years, SYDNEY
Vanessa, 48	Counsellor who wrestled with binge eating disorder for 25 years, SYDNEY
Sophie, 33	Postdoctoral neuroscience researcher with a family history of eating disorders who struggled with anorexia nervosa for 15 years, SYDNEY

Liam, 27	Tech company Chief Commercial Officer who grappled with anorexia nervosa for eight years, NEWCASTLE
Kaylee, 26	Creative art therapist & disability support worker whose anorexia nervosa robbed her childhood, WOLLONGONG
Jenni-Lee, 66	Author, speaker, award-winning writer & counsellor who grappled with anorexia nervosa for nine years, ADELAIDE
Lauren, 35	Mental health peer support worker & mother-of-three who battled anorexia nervosa for 14 years, ADELAIDE
Shannon, 48	Lived experience educator & dog lover who grappled with anorexia nervosa & bulimia nervosa for more than three decades, PERTH
Sophie, 27	Aspiring primary school teacher who wrestled with other specified feeding or eating disorder (OSFED) from 15 years of age, PERTH
DIGITAL MEDIA KIT	edgi2mediakit.org FEATURING DOWNLOADABLE INTERVIEW & OVERLAY WITH LISA CURRY AO
BROADCAST VISION	edgi2mediakit.org/VNR FEATURING DOWNLOADABLE GRABS WITH LISA CURRY AO + PIECE TO CAMERA
AUDIO GRABS	edgi2mediakit.org/ANR
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