

North Carolina media release

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UNC researchers seeking 6,000+ participants for world's largest eating disorders genetics study

Study to pinpoint genes influencing risk of developing eating disorders

University of North Carolina (UNC) researchers are seeking more than 6,000 participants aged 18 years and over, with first-hand experience of eating disorders to enroll in the world's largest ever genetic research study into three complex, devastating mental illnesses.

The ground-breaking Eating Disorders Genetics Initiative (EDGI) aims to identify the 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 recent survey results evaluating the impact of COVID-19 on Americans living with eating disorders performed by EDGI Principal Investigator, Distinguished Professor of Eating Disorders, Department of Psychiatry, School of Medicine, UNC, Professor Cynthia Bulik and her research team, support for those with eating disorders is more crucial than ever, given two-in-three survey respondents expressed concerns about their mental well-being.¹

"Individuals with current, or past experience of an eating disorder face unique risks due to the current pandemic.¹ While COVID-19 related factors, including the effects of quarantining, lack of clear information, and fear of infection, will influence the broader community's mental health,² they are likely to further impact those battling pre-existing mental illnesses, such as eating disorders.^{3,4}"

"Our new data show that over two-thirds are worried about the impact of the pandemic on their mental health – even more than are worried about the impact of COVID-19 on their physical health (46 percent),"¹ said Prof Bulik.

EDGI follows the ground-breaking advances made recently through the collaborative Anorexia Nervosa Genetics Initiative (ANGI), which revealed both psychiatric and metabolic origins of anorexia nervosa, explaining why people living with the disorder struggle to gain weight, despite their best efforts. The study further identified eight regions on the genome significantly associated with the illness.⁵

"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 diagnosis, management and treatment – an endeavor that is evidently even more critical during the current pandemic," Prof Bulik said.

Eating disorders are complex mental illnesses that for some, can lead to severe and permanent physical complications, and even death.^{6,7} 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.

"We are inviting all Americans, aged 18 and over, with first-hand experience of an eating disorder, to participate in this important genetics study," said Prof Bulik.

Participants need to be aged 18 years and over and have currently, or at any point in their lives experienced, anorexia nervosa, bulimia nervosa, or binge-eating disorder.

Those wishing to volunteer for, or learn more about EDGI, can visit www.edgi.org, email EDGI@unc.edu or call (984) 974-3798.

According to Prof Laura Thornton, Deputy Director, EDGI, UNC, who has a PhD in Genetics, findings from family and twin studies indicate eating disorders are heritable.⁸

"To further these studies, EDGI researchers will analyze participant saliva samples to point toward specific genes associated with eating disorders. DNA will be extracted from the saliva samples and genotyped to provide a read out of each participant's genetic code."

"Genetic variants will 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 illnesses,"^{9,10} Prof Thornton said.

Nearly half of all individuals with eating disorders experience other mental health conditions at some point during their lives.¹¹ Therefore, by comparing the EDGI samples with samples from individuals with other disorders will also help the researchers to understand the genetic relationship among eating disorders and commonly co-occurring conditions, such as depression, anxiety disorders, substance use problems, as well as other medical illnesses including metabolic conditions.^{12,13}

According to author, founder and Executive Director, Families Empowered And Supporting Treatment for Eating Disorders (F.E.A.S.T), Ms Laura Collins Lyster-Mensh, Virginia, eating disorders are not a choice, but rather, are biologically-influenced medical illnesses¹⁴ that can cause significant distress, and affect the lives of individuals, their families, carers, partners, and friends.¹⁵

"Eating disorders are recognized as a significant public health concern,¹⁶ which appear to be on the rise, noting the average prevalence of eating disorders has more than doubled since 2000.¹⁶ Concerningly, eating disorders have one of the highest mortality rates of any mental illness.¹⁷

"People of all genders, ages, body sizes, races, ethnicities, and socioeconomic backgrounds can be affected by an eating disorder. Those with an eating disorder may also appear to be healthy, yet be extremely ill,"¹⁴ said Ms Collins Lyster-Mensh.

Eating disorders advocate, Marybeth, 49, North Carolina, lived with anorexia nervosa, bulimia nervosa, and binge-eating disorder for more than 20 grueling years, rendering her unable to focus on anything else besides maintaining her restrictive diet, and exercising excessively.

After entering college, her disordered eating behaviors escalated. She spent Monday to Friday restricting her food intake, and exercising excessively, and her weekends binge eating – a vicious cycle which she struggled to break.

"Living with an eating disorder is like having a voice in your head telling you what to do all the time. There is no rest and no escape. It was a horrible, isolating existence. My family felt like they were walking on eggshells around me. We were in a constant state of stress," Marybeth said.

Having since founded Epiphany, an organization offering support and treatment to those living with eating disorders, Marybeth is passionate about helping others begin their journey toward recovery.

She believes genes play a significant role in the development of an eating disorder, especially given her family history of disordered eating, and is a strong advocate for EDGI.

"It's essential that we identify the underlying genetic causes of eating disorders, to save lives and improve treatment options available to those living with eating disorders. Families need to know that eating disorders are not a choice, and those living with an eating disorder need to know there is no shame whatsoever in the struggle."

"I always say that my worst day in recovery is 100,000 times better than my best day living with an eating disorder," said Marybeth.

Should you suspect that you, or a loved one, may be living with an eating disorder, speak to your local healthcare professional without delay. US patient support services offering helpline services include:

- **National Eating Disorder Association – Call (800) 931-2237, Crisis text 741741**
- **National Association of Anorexia Nervosa (ANAD) – Call (630) 577-1330.**

To volunteer for, or learn more about EDGI, head to www.edgi.org, email EDGI@unc.edu or call (984) 974- 3798.

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