

## Congressional Briefing Talk on Eating Disorders Research

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350,000 Americans suffer from insulin dependent diabetes. 400,000 Americans have multiple sclerosis. 2.4 million Americans have schizophrenia. 5.4 million Americans struggle with Alzheimer's disease. 9 million Americans have an eating disorder.

More than 20 years ago I was an undergraduate at Cornell University. I met some of these individuals. As a fellow student, I was dumbfounded. As a future researcher, I wondered how an emotional problem could destroy someone's body and mind. As a future clinician, I wanted to help them get their lives back.

Now we have much more data on how many people are afflicted with eating disorders than we did back then. Anorexia nervosa is characterized by starvation and a distorted perception of one's body image. Bulimia nervosa involves recurrent binge eating and purging, while binge eating disorder is characterized by bingeing without purging. 0.6% of the population will experience anorexia nervosa at some point in their lives, 1.1% will experience bulimia nervosa, and 3.9% will experience binge eating disorder. In addition, rates of anorexia nervosa have accelerated over the past century. And all of these numbers fail to consider the largest group of eating disordered individuals. *More than half* of people receiving treatment for an eating disorder have a diagnosis of eating disorder "not otherwise specified"; they

don't fit clearly into the other diagnostic categories. Therefore, all of the statistics presented today in all likelihood woefully underestimate what is really going on.

So who exactly is affected? We used to believe that there was a 10:1 ratio of women to men with eating disorders; now we know that the ratio is closer to 3 or 4:1. Far larger numbers of men have eating disorders than we recently thought. Also, eating disorders occur in every racial group that has been studied, which includes Caucasians, African Americans, Latinas, Asian Americans and Native Americans. In addition, while adolescents and young adults are disproportionately affected by eating disorders, children and middle-aged adults also suffer.

Ok, so we know who eating disorders affect, but how serious are they, really? Let's answer this by looking at a typical example of how things might unfold with say, someone suffering from anorexia nervosa. From numerous studies of twins and other siblings, we know that an individual is born with a genetic constitution that makes him or her at increased risk for developing an eating disorder due to his or her natural temperament or serotonin regulatory system, for instance. Then there is exposure to environmental risk factors, that we may all be exposed to, but for a genetically vulnerable individual such exposure can result in the onset of illness. Weight loss ensues, resulting in cognitive deficits which further maintain the disorder. The person is robbed of normal capacity for thought. As weight decreases further, physiological and cognitive mechanisms make it extremely difficult to reverse the starvation cycle. In addition, numerous psychological and physical consequences ensue. These include depression, hair loss, stomach pain, lowered testosterone levels, infertility, stress fractures, irreversible osteoporosis, growth retardation, loss of brain tissue, kidney

damage, multi-organ failure, seizures, electrolyte imbalances, dangerously low heart rate, decreased heart size and strength, and other cardiac abnormalities that can lead to sudden death.

In fact, anorexia nervosa has the *highest death rate* of any psychiatric illness. 10-20% of those treated will eventually die. The mortality rate is *more than 12 times higher* than the annual death rate from all causes of death for females aged 15-24 in the general population.

People with eating disorders, especially anorexia nervosa, are often tormented with questions like, "Why don't you just eat?" The answer is that when the body is starved, the brain doesn't work in the same way. Thinking becomes rigid and problem-solving is compromised. Malnutrition and weight loss produce alterations in neurobiology, which worsen mood and other symptoms. Years of being in this state results in brain damage. What many people don't understand is that if you put someone with an eating disorder on a desert island alone, that person will still have an eating disorder. It doesn't make a difference. The person is trapped. Once the eating disorder takes hold, it has little to do with other people. While societal factors influence the development of eating disorders in vulnerable individuals, after it begins, a self-perpetuating cycle takes hold. An eating disorder is not a choice- it is a terrible illness that hijacks the body and the mind and affects every waking moment of the individual who is suffering. It is relentless and once it gets a stranglehold on you, it's extremely hard to break free without adequate, appropriate treatment.

Resources devoted to eating disorders have been disproportionately small. Why? One reason is likely due to a lack of understanding, or perhaps misunderstanding, about the causes of these illnesses. Similar to other diseases like heart disease and alcoholism, eating disorders are caused by a complex interaction among various genetic and environmental factors. When you look at who develops an eating disorder in the population, more than 50% of all of the factors that cause the illness are inherited. This “heritability” rate is comparable to what has been found among other illnesses like schizophrenia and bipolar disorder. Schizophrenia, bipolar disorder and eating disorders are *not* a choice; they are all real and devastating illnesses.

We have made great strides in the eating disorders field utilizing the most recent genetic methodological approaches available. We know that genes substantially contribute to risk for eating disorders, but we need more research to identify exactly which genes and the mechanisms by which they confer risk. If we can identify even one group of genes, this would move the field forward in understanding not only the physiological mechanisms underlying eating disorders, but also how environmental factors influence those people at increased genetic risk. The goal is for this research to ultimately direct us toward new targets for prevention and treatment.

Many clinicians and policy makers have long assumed that the individual and societal impact of psychiatric disorders was certainly less significant than those illnesses considered “medical disorders.” However, we now know from the Medical Outcome Study, a landmark project of 11,000 individuals with psychiatric problems, that psychiatric

illnesses are even more impairing than chronic medical conditions such as hypertension, diabetes, arthritis, and pulmonary disease in terms of physical functioning, role functioning, social functioning, days in bed, and overall physical health. The Medical Outcome Study examined individuals with “garden variety” psychiatric disorders like depression. Given the morbidity and mortality of eating disorders already discussed, we know that these are clearly not “garden variety” illnesses and likely, in fact, result in even greater impairment than what was found in this renowned study.

Therefore, it’s absolutely critical to the physical and psychological health of approximately 9 million individuals, as well as their family members (not to mention the societal cost), to have legislation to support specific research initiatives, improve access to adequate and appropriate treatment, and support education and prevention of these disorders, which have been historically underfunded and undertreated in comparison to other illnesses that are less widespread and less deadly. The FREED Act, which is comprehensive legislation that addresses research, treatment, education and prevention of eating disorders will make huge strides toward diminishing the devastating personal, familial, and societal impact of eating disorders.

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