

# Ambiguous results in screening for celiac disease among young people

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Most children who undergo screening to detect gluten intolerance, celiac disease, can handle it well. However, many people feel that the discovery of the disease and the treatment they receive does not provide a better quality of life. Katrina Nordyke will address this topic as she defends her PhD thesis at Umeå University on November 15.

Celiac [disease](#) is a chronic disease attributable to genetic susceptibility which causes damage to the small intestine by the intake of gluten in the diet. It is estimated that between 1 and 3 percent of the population have the disease, but the number of unreported cases is high and most sufferers go undiagnosed. Sweden has higher rates of [coeliac disease](#) than the rest of the western world.

The benefits of screening for [celiac disease](#) in the general population is controversial and the consequences of being diagnosed when screening has been unclear. Sweden has had an epidemic of celiac disease.

Therefore, researchers at Umeå University conducted the population-based research project ETICS, Exploring the Iceberg of Celiacs in Sweden, to investigate issues arising with celiac disease and screening for the disease. All sixth graders in five regions in Sweden were invited to participate in the study during 2005/2006 and 2009/2010.

In her thesis, Katrina Nordyke examines the experiences and results of screening to detect celiac disease in these children. She notes that the results are ambiguous.

"Most kids can handle the concerns of the screening examination and thoughts about the disease may present. However, there was no consensus that the detection of disease and treatment results in an increased health-related quality of life.", says Katrina Nordyke.

The children involved in ETICS wrote short stories where they described their screening experience before they received their screening results. The stories show that some children experienced the fear and anxiety, but as a whole they managed the screening well. The kids also filled out surveys about their health-related quality of life at the time of the screening and one year after diagnosis. Finally, those who received a celiac diagnosis from the screening wrote new stories one and five years after diagnosis.

According to Katrina Nordyke, the stories show that the threat from complications caused by the disease affected how young people experienced the diagnosis, how they coped with the gluten-free diet and what they thought of screening for celiac disease.

"Five years after diagnosis of celiac disease, the majority of young people have learned to live with the disease, and acquired habits and strategies to cope with living with gluten-free diet. But at the same time some of these [young people](#) still doubt the benefits of having been diagnosed with celiac disease through the screening", says Katrina Nordyke.

Katrina Nordyke comes from the United States where she worked as a nurse. Today, she lives in Umeå, where she received a Masters Degree in Public Health and is a PhD student at the Department of Public Health and Clinical Medicine, Umeå University.

**More information:** [urn.kb.se/resolve?urn=urn:nbn:se:umu:diva-81689](http://urn.kb.se/resolve?urn=urn:nbn:se:umu:diva-81689)

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