

Celiac Disease and Gluten Sensitivity in School-Age Kids: Symptoms, Prevalence, and Support Resources

I disclose the absence of personal financial relationships with commercial interests relevant to this educational activity within the past 12 months

Lola O'Rourke, MS, RDN, Education Coordinator, Gluten Intolerance Group - gig.outreach@gluten.org

Copyright © 2021 Gluten Intolerance Group



GLUTEN INTOLERANCE GROUP™



Support Resources Available from Gluten Intolerance Group (GIG) and its Generation GF Program

- GIG Generation GF support groups educate and empower gluten-free youth and provide peer interactions.
- Membership program linking 3500+ Generation GF youth from seven countries.
- Print magazines promoting healthy and fun gluten-free living geared toward children and their parents.
- Extensive educational bulletins and articles on relevant topics.
- Printable, customizable “Letter to Teacher” and “Field Trip Letters” for parents/families, to facilitate communications with educators.
- Summer camps helping gluten-free children feel less isolated due to dietary limitations.
- Teen Summit providing a platform to discuss living gluten-free as a teen with expert speakers.
- Mentor program facilitating one-on-one peer-based support between gluten-free kids and teens.

REFERENCES:

1. Caio, G., & Volta, U. (2019). Celiac disease: a comprehensive current review. *BMC Medicine*. doi: 10.1186/s12916-019-1380-z
2. Green, P. H., Krishnareddy, S. H., & Lebowitz, B. H. (2015). Clinical Manifestations of Celiac Disease. *Dig Dis*, 137-140. doi: 10.1159/000370204
3. Lebowitz, B. F., Ludvigsson, J. H., & Green, P.H. (2015). Celiac Disease and Non-Celiac Gluten Sensitivity. *BMJ*. doi: 10.1136/bmj.h4347
4. Lee, A. R., Wolf, R. H. R., Contento, I., Verdelli, H., & Green, P.H. (2015). Coeliac disease: the association between quality of life and social support network participation. *Journal of Human Nutrition and Dietetics*, 29(3), 383-390. doi: 10.1111/jhn.12319
5. Leffler, D. A., Green, P. H., & Fasano, A. (2015). Extraintestinal manifestations of coeliac disease. *Nature Reviews Gastroenterology & Hepatology*, 12(10), 561-571. doi: 10.1038/nrgastro.2015.131
6. Sansotta, N., Amirikian, K., Guandalini, S., & Jericho, H. (2018). Celiac Disease Symptom Resolution: Effectiveness of the Gluten-Free Diet. *Journal of Pediatric Gastroenterology and Nutrition*, 66(1), 48-52. doi: 10.1097/MPG.0000000000001634
7. Zingone, F. L., Swift, G. R., Card, T. R., Sanders, D. S., Ludvigsson, J. F., & Bai, J. C. (2015). Psychological morbidity of celiac disease: A review of the literature. *United European Gastroenterol J*, 136-145. doi: 10.1177/2050640614560786

BACKGROUND

Celiac disease

- A serious autoimmune condition
- Affects approximately 1% of the global population.

Non-celiac gluten sensitivity

- Poorly defined
- Prevalence is unknown but may be even higher.

200+ Symptoms associated with both disorders

50% Of individuals with celiac disease are undiagnosed (estimate)

5+ Number of years (estimate) it can take to diagnose celiac disease

GLUTEN-FREE DIET = TREATMENT

CELIAC DISEASE

- Undiagnosed/untreated celiac disease
- Inflammation and intestinal cell damage
- Malabsorption of nutrients that are essential to growth and development
- Potentially serious long-term health issues such as low bone mineral density

NON-CELIAC GLUTEN SENSITIVITY

- Undiagnosed/untreated non-celiac gluten sensitivity
- Significantly impacts quality of life but no intestinal damage and related health issues

Increased awareness of celiac disease among health professionals is expected to increase rates of diagnosis.

SCHOOL NURSES

- May be among the first health professionals to become aware of symptoms that may be indicative of celiac disease or non-celiac gluten sensitivity in school-age children.
- Are in a position to inform families of related educational and support resources.

SYMPTOMS

- Celiac disease and non-celiac gluten sensitivity share common symptoms, both gastrointestinal and extra-intestinal.
- Can occur in all body systems and may include headaches, abdominal pain, nausea, irritability, canker sores, anemia, delayed growth, failure to thrive, and delayed puberty, among many others.

PREVALENCE

- Celiac disease: Approximately 1%; can develop at any age.
 - 5-15% if present in first-degree relatives (screening is recommended).
- Non-celiac gluten sensitivity: unknown, but may be higher than that of celiac disease.

SCREENING

- Blood screening for antibodies is the first step in celiac disease diagnosis.
- Prior to a potential diagnosis of non-celiac gluten sensitivity, celiac disease should be ruled out.

TREATMENT

- A strict gluten-free diet is currently the only treatment for celiac disease, and is also the treatment for non-celiac gluten sensitivity.

CHALLENGES

THE GLUTEN-FREE DIET

- Can be difficult to implement
- Can be a psychological burden
- Can impact virtually all aspects of a child's life and impact overall quality of life

SUPPORT

Education and support are essential.

Participation in social support networks has been found to improve quality of life.

Non-profit organizations such as the Gluten Intolerance Group and numerous clinical celiac disease centers offer educational and support resources.

The mission of the Gluten Intolerance Group is to make life easier for everyone living gluten-free. This includes its Generation GF program which provides support and education for gluten-free children, teens and young adults.

KEY POINTS

- Increased awareness of gluten-related disorders among school nurses and other health professionals is important to help mitigate the adverse health and quality of life outcomes which can result from delayed diagnosis.
- Increased access to educational and support resources, such as those provided by the Gluten Intolerance Group, can improve adherence to a gluten-free diet, reduce psychological burden, and improve quality of life among school-age children with gluten-related disorders.

Timely diagnosis + successful adoption of a gluten-free diet



Reduction in adverse health outcomes and improved quality of life in school-age children