

Safety of Oats for People with Celiac Disease

Background

Celiac Disease (CD) is a multifactorial (polygenic and environmental) immune-mediated gastrointestinal disorder that affects about 1 in 100 to 1 in 133 individuals in North America.^{1,28,29,43} This frequency equates to about 238,000 affected individuals in Canada⁵⁴ and 2,150,000² in the U.S., for a total of about 2,380,000 in North America. There is very little information on the prevalence of wheat sensitivity in the North American population, but the addition of these individuals could place the total North American population with celiac disease and wheat sensitivities at well over 3,000,000 individuals.

Celiac Disease is characterized by sensitivity to the gliadin component of wheat, barley, rye, triticale, kamut and spelt (WBR) glutes.³ Oats are a more distant cousin, and the storage proteins in them are sufficiently different from those of WBR so that it appears that they are not toxic to people with CD.^{1,11,14} However, because of cross-contamination with WBR during growth, harvesting, transport, storage and processing, oat food products have been off limits to people with CD. Affected individuals have diarrhea, abdominal cramping, pain and abdominal distention. Untreated, CD may lead to vitamin and mineral deficiencies, failure to thrive, delayed puberty, infertility, osteoporosis, etc. Currently the only treatment is complete abstention from WBR for life, and most affected individuals show remission after exclusion of dietary gluten.

Why oats for people with celiac disease?

Studies indicate that:

- Oats increase palatability for people with CD who are otherwise completely restricted in their diets.²²
- Rolled oats and whole oat flour add texture, flavor and fiber to gluten-free baked products made with rice, potato and tapioca flours and starches. When used as the sole source of flour, oat flour gives a firmer, more cohesive and less crumbly textured baked product.³²
- In oats, avenin accounts for 10 – 15% of total protein whereas in WBR the protein is 30 – 60 % gliadin.³ The putative amino acid sequence is much less prevalent in avenin than in gliadin and therefore, oats are comparatively better tolerated by the person with CD than are WBR.³³
- The injurious agent in WBR, for people with CD, is in the ethanol soluble fraction, the gliadins. This toxicity remains after peptic–tryptic digestion of WBR, but not after such digestion of avenin, which suggests that avenin is not harmful to CD people.

Thus, there was a need among people with celiac disease for a source of oats with no cross-contamination with wheat, barley, rye, triticale, kamut and spelt, which would significantly improve their quality of life.

Current status of pure, uncontaminated oats:

Until recently, there have not been any pure, uncontaminated oats in Canada⁴ or the U.S.,²⁷ and a recent survey³⁶ of the gluten content in commercially available oat products in the U.S. showed that all are contaminated. In a recent study looking at the contamination of grains, including oats, shows that 80% of oat products that they analysed and that are sold in Europe, Canada and the United States were contaminated with gluten-containing cereals, predominantly barley⁵³. While some packages from a particular manufacturer may have acceptably low levels of gluten, others from the same manufacturer do not,³⁶ so CD individuals cannot presently rely on “off-the-shelf” oat products as being safe for consumption. However, a number of European and North American studies conducted over the past 8-10 years have generally shown that moderate amounts of oats are well-tolerated in the diets of both

adults^{5-7,10-13,15, 47-52} and children^{8,9,14,45, 46} with celiac disease. In-vitro studies have confirmed the validity of clinical studies.³⁰ On the other hand, several studies have suggested that oats can provoke typical symptoms of CD in at least some patients,^{16,18,41} although not in all of them.^{17,35}

In consideration of the above and other information, a number of prominent U.S. medical centres, and North American and UK celiac disease support groups have commented on their web sites about the safety of oats in the diets of people with CD. ☹ indicates no clear position one way or the other.

Medical Centres:

- 👉 Beth Israel Deaconess - <http://www.bidmc.org/CentersandDepartments/Departments/DigestiveDiseaseCenter/CeliacDiseaseCenter/RecommendationsonOatConsumption.aspx>
- 👉 Columbia University - www.celiacdiseasecenter.columbia.edu or <http://www.glutenfreeindy.com/contamination/oats.htm>
- 👉 Harvard - www.intelihealth.com/IH/ihtIH/WSHPO000/25792/9681.html#treat
- 👉 Stanford University Medical Center - <http://stanfordhospital.org/clinicsmedServices/medicalServices/clinicalNutrition/clinicalNutrition.html>
- ☹ University of Maryland - <http://www.celiaccenter.org/>
- ☹ Mayo Clinic - <http://www.mayoclinic.com/invoke.cfm?objectid=0B50B26D-34AE-4F43-843BDA653DDEF6E3&dsection=8>
- ☹ Yale University School of Medicine - <http://ymghealthinfo.org/content.asp?page=P00361>

Government Bodies:

- 👉 U.S. National Institutes of Health - <http://consensus.nih.gov/2004/2004CeliacDisease118PDF.pdf>

Associations:

- 👉 Canadian Celiac Association - http://www.celiac.ca/position_on_oats.php
- 👉 Celiac Disease Foundation - <http://www.celiac.org/cd-main.php>
- 👉 Coeliac UK - http://www.coeliac.org.uk/healthcare_professionals/dietary_management/1123.asp
- 👉 Gluten Intolerance Group - <http://www.gluten.net/diet.php>
- 👉 Dietitians of Canada – DC PEN – Practice-based Evidence in Nutrition (membership)
- ☹ American Dietetic Association - ADA Nutrition Care Manual (membership)
- ☹ North American Society for Pediatric Gastroenterology, Hepatology and Nutrition http://www.naspghan.org/PDF/PositionPapers/celiac_guideline_2004_jpgn.pdf
- ☹ Celiac Sprue Association (US) – while website doesn't reflect it, they are now saying pure, uncontaminated oats may be OK for some people with celiac disease – 2 years after diagnosis www.csaceliacs.org/InfoonOats.php or www.csaceliacs.org/celiac_treatment.php
- 👉 The Celiac Society of Australia - <http://www.coeliacsociety.com.au/diet.html>

Individuals:

- 👉 Shelley Case RD – if pure, uncontaminated oats and in moderate amounts
- 👉 Tricia Thompson RD – if uncontaminated oats available I would support inclusion in moderation
- 👉 Cynthia Kupper RD – if pure, uncontaminated then moderation is OK.

Most of the organizations, in their expressions of “reservations”, find that the main reason for avoiding oats is because of possible cross-contamination with WBR, implying, if not stating, that if this WBR cross-contamination were removed, moderate amounts of oat consumption should be acceptable for most CD people. In general, those who support the use of moderate amounts of oats by most people with celiac disease suggest a maximum of 50 gm per day for adults⁴² and 25 gm per day for children. The American and Canadian Dietetic Associations conclude that people with CD who choose to eat oats should “limit their consumption to amounts found to be safe in several studies (approximately one half cup of dry whole-grain rolled oats per day)”.^{19,31,39}

However, it should be noted that, while intermediate-term studies (5-10 years) of the effects of oats on people with CD have been started and reported,^{11, 48-50} no long-term studies (10-30 years or more) have been completed. Thus, at this time there is no conclusive evidence that oats are safe for consumption by people with CD in the long term, and it should not be assumed that long-term consumption of oats is safe for them.²⁰ Furthermore, because there is a wide range of sensitivity to gluten among people with CD,^{21,28} there will inevitably be some who should not include oats in their diets.

Studies conducted over 6 months on children who ate 24 grams of oats per day did show some decrease in intestinal biopsy score and decreased IEL count.⁹ When 39 people were studied for a period of 1 year with 30 – 50 grams of oats per day there was no change in the villous structure but the GI symptoms increased.¹⁸ This was attributed to cross contamination. There was no stimulus for endomysial antibodies or inflammatory cytokine production. An in-vitro method to assess the immunological evidence to show no harmful effect of oats in people with CD was done revealing no microvilli architectural change, and there was no inflammatory response.³⁰ A recent 2 year controlled trial with 7 year clinical follow-up study in 32 children showed the oats had no detrimental effect on intestinal histology or serology during the 2 year trail⁴⁶. 19 of these children who continued to eat oats were follow-up clinically for up to 7 years, with a mean follow-up of 5 years – all remained asymptomatic, had normal development and non was suspected of relapse of CD based on clinical and serological grounds therefore no additional small bowel biopsies were carried out. Another recent study of 10 patients who ingested 50 g of oats daily for 3 months investigated them for possible evidence of immune activation. None of the patients developed clinical or laboratory evidence of adverse effects.⁴⁷ Another recent study of 82 adults with celiac disease who were on a gluten-free diet and who had been eating pure oats for more than 6 months, the ingestion of oats did not cause increased levels of IgA.⁵⁰ Hence, moderate amounts of oats could be tolerated.

However, a recent study of 9 patients who had exposure to uncontaminated oats (50 grams for 12 weeks) did show T cell inflammation.³⁵ Oat intolerance can cause complications which could be proven with extended clinical follow up. Monitoring of T cell responses to avenin epitopes may potentially identify individuals who are at risk of developing intolerance. This monitoring will also help in following people with CD who are clinically tolerant to Oats. In studies where withdrawals occurred, most withdrawals were by subjects who found it difficult to follow the diet and most often this was because of a recurrence of symptoms as a result of the oats being contaminated from other sources.⁹ Recent research in celiac disease has been summarized by Robins and Howdle and the National Institutes of Health.^{1,38}

Finally, it is well established that people with celiac disease do want oats in their diets, both for their nutritional contribution (fiber, B vitamins) and for palatability^{22-25,40} reasons. This would result in an improved quality of life.³⁷ There has been some interest in North America in developing methods to remove contaminating grains from oats.²⁶

References:

1. National Institutes of Health - Consensus Development Conference Statement: Celiac Disease June 28-30, 2004. <http://consensus.nih.gov/2004/2004CeliacDisease118PDF.pdf>
2. Total U.S. Population. From year 2000 census. www.factmonster.com/ipka/A0004997.html
3. Wieser H. Prolamins in cereals. In: Lohiniemi S, Collin P, Maki M, eds. Changing features of coeliac disease. Tampere: The Finnish Coeliac Society, pp 25-30; 1998.
4. Rashid M, Canadian Celiac Association. "CELIAC NEWS" Statement on the Safety of Oats. February 2003. www.celiac.ca/Articles/2003-17-1.html (This statement has been reiterated by the CCA in their quarterly newsletter *Celiac News* for the March, 2005 issue.)
5. Dissanayake AS, Truelove SC, Whitehead R. Lack of harmful effect of oats on small-intestinal mucosa in coeliac disease. *BMJ* 4: 189-191; 1974. Citation only available from: <http://www.ncbi.nlm.nih.gov/pubmed/4417208?dopt=Abstract>; accessed 22 July 2005.
6. Janatuinen EK, Pikkarainen PH, Kempainen TA, et al. A comparison of diets with and without oats in adults with celiac disease. *N Engl J Med* 333:1033-1037; 1995. Available from: <http://content.nejm.org/cgi/content/abstract/333/16/1033>; accessed 22 July 2005.
7. Srinivasan U, Leonard N, Jones E, et al. Absence of oats toxicity in adult coeliac disease. *BMJ* 313:1300-1301; 1996. Available from: <http://bmj.bmjournals.com/cgi/content/full/313/7068/1300>; accessed 22 July 2005.
8. Holm K. No harm of oats in the diet of children with newly and previously diagnosed celiac disease. *J Pediatr Gastroenterol Nutr.* 26:549- ; 1998. (We have been unable to locate this.)
9. Hoffenberg EJ, Haas J, Drescher A, et al. A trial of oats in children with newly diagnosed celiac disease. *J Pediatr* 137:361-366; 2000. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10969261?dopt=Abstract>; accessed 22 July 2005.
10. Janatuinen EK, Kempainen TA, Pikkarainen PH, et al. Lack of cellular and humoral immunological responses to oats in adults with celiac disease. *Gut* 46:327-331; 2000. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10673292>; accessed 24 Aug 2009.
11. Janatuinen EK, Kempainen TA, Julkunen RJK, et al. No harm from five year ingestion of oats in celiac disease. *Gut* 50:332-335; 2002. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/11839710>; accessed 24 Aug 2009.
12. Storsrud S, Olsson M, Arvidsson LR, et al. Adult coeliac patients do tolerate large amounts of oats. *Eur J Clin Nutr* 57:163-169; 2003. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12548312?dopt=Abstract>; accessed 22 July 2005.
13. Murray JA, Watson T, Clearman B, Mitros F. Effect of a gluten-free diet on gastrointestinal symptoms in celiac disease. *Amer J Clin Nutr.* 79:669-673; 2004. Available from: <http://www.ajcn.org/cgi/content/full/79/4/669>; accessed 22 July 2005.
14. Hogberg L, Laurin P, Falth-Magnusson K et al. Oats to children with newly diagnosed celiac disease: a randomized double blind study. *Gut* 53:649-654; May 2004. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15082581>; accessed 24 Aug 2009.
15. Collin P, Thorell L, Kaukinen K, Maki M. The safe threshold of gluten contamination in gluten-free products. Can trace amounts be accepted in the treatment of celiac disease? *Alimentary Pharmacology & Therapeutics* 19:1277-1283; June 2004. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15191509?dopt=Abstract>; accessed 22 July 2005.
16. Baker PG, Read AE. Oats and barley toxicity in celiac patients. *Postgrad Med J* 52:264-268. 1976. Citation only available from: <http://www.ncbi.nlm.nih.gov/pubmed/959100?dopt=Abstract>; accessed 22 July 2005.

17. Lundin KE, Nilsen EM, Scott HG, et al. Oats induced villous atrophy in celiac disease. *Gut* 52:1649-1652; 2003. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/14570737>; accessed 24 Aug 2009.
18. Peräaho M, Kaukinen K, Mustalahti K, et al. Effect of an oats-containing gluten-free diet on symptoms and quality of life in celiac disease. A randomized study. *Scand J Gastroenterol* 39(1):27-31; 2004. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/14992558?dopt=Abstract>; accessed 22 July 2005.
19. Thompson T. Oats and the gluten-free diet. *J Amer Dietetic Assoc* 103(3):376-379. March 2003. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12616264?dopt=Abstract>; accessed 22 July 2005.
20. Branski D. Oats in celiac disease. *N Engl J Med*. 334:865-866; 1996. Citation only available from: <http://www.ncbi.nlm.nih.gov/pubmed/8596567?dopt=Abstract>; accessed 22 July 2005.
21. Celiac Disease (CD). "Treatment: There is great variation in sensitivity to gluten among those with Celiac Disease..." <http://www.celiac.ca/celiac.php> Jan 26, 2004 Update.
22. Kumar PJ, Walker-Smith J, Milla P, et al. The teen-age celiac: follow-up study of 102 patients. *Arch Dis Child* 63:916-920; 1988. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/3415327?dopt=Abstract>; accessed 22 July 2005.
23. Duthie M. Personal communication. (Mrs. Duthie is currently President of the Quebec Chapter of the Canadian Celiac Association.) Autumn, 2004.
24. Perry LJD and Cream Hill Estates. Oats in the celiac diet: A survey of celiac attitudes toward inclusion, format and cost. Montreal, Quebec, Canada; in progress, Autumn 2004 - .
25. Perry TB. Personal observation. The multiple Scandinavian and other studies of oats in celiac diets have been inspired at least in part by the perceived benefits to people with celiac disease that would be derived from their inclusion, if oats could be shown to be safe for this sub-group of the population.
26. Burrows VD. Hulless Oats. In: *Specialty Grains for Food and Feed*. Edited by Abdel-Aal E-SM, Wood P. American Association of Cereal Chemists. DOI: 10:1094/AACC 27411-09, 2005. pp 236-238.
27. Adams S. Comment concluding an article by Kasarda DD. Celiac.com, 2004. http://www.celiac.com/st_prod.html?p_prodid=196
28. Gallagher E, Gormley TR, Arendt EK. Recent advances in the formulation of gluten-free cereal-based products. *Food Science & Technology* 15:143-152; 2004. Abstract available from: <http://cat.inist.fr/?aModele=afficheN&cpsidt=15621135>; accessed 24 Aug 2009.
29. Canadian Celiac Association. <http://www.celiac.ca/celiac.php>; accessed 24 Aug 2009.
30. Picarelli A, DiTola M, Sabbatella, L, et al. Immunologic evidence of no harmful effect of oats in celiac disease. *Am J Clin Nutr* 74:137-140; 2001. Available from: <http://www.ajcn.org/cgi/content/full/74/1/137>; accessed 22 July 2005.
31. Adams S. American Dietetic Association concludes uncontaminated oats safe for those with celiac disease. Celiac.com, 2003. www.celiac.com/st_prod.html?p_prodid=813
32. Fenster C. *Wheat – Free recipes and Menus*. 3rd edition. Littleton (CO): Savory Palate, Inc; 2004. Information available from: <http://www.savorypalate.com/wfrma.aspx>; accessed 24 Aug 2009.
33. Hardman CM, Garioch JJ, Leonard JN, et al. Absence of toxicity of oats in patients with dermatitis herpetiformis. *N Engl J Med*: 337: 1884-7; 1997. Available from: <http://content.nejm.org/cgi/content/abstract/337/26/1884>; accessed 22 July 2005.

34. Kendall MJ, Cox PS, Schneider R, et al. Gluten sub-fractions in celiac disease. *Lancet*; Vol. 2 ; 1065-7; 1972. Citation only available from:
<http://www.ncbi.nlm.nih.gov/pubmed/4117383?dopt=Abstract>; accessed 22 July 2005.
35. Arentz-Hansen H, Flackenstein B, Molberg Y, et al. The Molecular Basis for Oat Intolerance in Patients with Celiac Disease; *PLOS Medicine* 2004. Available from:
<http://www.pubmedcentral.gov/articlerender.fcgi?tool=pubmed&pubmedid=15526039>; accessed 22 July 2005.
36. Thompson T. Gluten contamination of commercial oat products in the United States. *N Engl J Med*: 351:19:2021-2022; November 4, 2004. Available from:
<http://content.nejm.org/cgi/content/extract/351/19/2021-a>; accessed 22 July 2005.
37. Cranney A, Zarkadas M, Graham ID, Switzer C. The Canadian celiac health survey – the Ottawa chapter pilot. *BMC Gastroenterology*: 3:8; May, 2003. Available from:
<http://www.biomedcentral.com/1471-230X/3/8>; accessed 22 July 2005.
38. Robins G, Howdle PD. Advances in celiac disease. *Curr Opin Gastroenterol* 20(2):95-103; 2004. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/15703628>; accessed 24 Aug 2009.
39. American Dietetic Association – Nutrition Care Manual. <http://www.eatright.org/Public/> (membership required)
40. Peräaho M, Collin P, Kaukinen K, Kekkonen L, Miettinen S, Maki, M. Oats can diversify a gluten-free diet in celiac disease and dermatitis herpetiformis. *J Amer Dietetic Assoc.*104:7:1148-1150, July, 2004. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/15215774?dopt=Abstract>; accessed 22 July 2005.
41. Spaenij-Dekking EH, Kooy-Winkelaar EM, Nieuwenhuizen WF et al. A novel and sensitive method of T cell stimulatory epitopes of α/β - and γ -gliadin. *Gut* 53:1267-73; 2004. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15306583>; accessed 22 July 2005.
42. Farrell RJ, Kelly CP. Celiac Sprue. *N Engl J Med* 346:180-8; 2002. Available from:
<http://content.nejm.org/cgi/content/extract/346/3/180>; accessed 22 July 2005.
43. Fasano A, Berti I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States; a large multi-center study. *Arch Intern Med* 163:286-292; 2003. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12578508?dopt=Abstract>; accessed 22 July 2005.
44. Kupper, Cynthia. Dietary Guidelines and Implementation for Celiac Disease. *Gastroenterology* 128:S121–S127; 2005. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/15825119?dopt=Abstract>; accessed 22 July 2005.
45. Hollen, E. et al. Celiac children on a gluten-free diet with or without oats display equal anti-avenin antibody titres. *Scandinavian Journal of Gastroenterology* 41:42-47; 2006. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/16373275?dopt=Abstract>; accessed 5 January 2006.
46. Holm K, Mäki M, Vuolteenaho N, Mustalahti K, Ashorn M, Ruuska T and Kaukinens K. Oats in the treatment of childhood coeliac disease: a 2-year controlled trial and a long-term clinical follow-up study. *Alimentary Pharmacology and Therapeutics*. 2006; 23:1463-1472. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16373275?dopt=Abstract>; accessed 21 May 2006.
47. Srinivasan U, Jones E, Carolan J and Feighery C. Immunohistochemical analysis of coeliac mucosa following ingestion of oats. *Clin Exp Immunol*. 2006; 144(2):197-203. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16634791?dopt=Abstract>; accessed 21 May 2006.
48. Kempainen T, Janatuinen E, Holm K, Kosma VM, Heikkinen M, Ma M, Laurila K, Uusitupa M and Julkunen R. No observed local immunological response at cell level after five years of oats in adult coeliac disease. *Scandinavian Journal of Gastroenterology*. 2007; 42(1):54-59. Available

- from: <http://www.ncbi.nlm.nih.gov/pubmed/17190763?dopt=AbstractPlus>; accessed 6 January 2007.
49. Garsed K and Scott B. Can oats be taken in a gluten-free diet? A systematic review. *Scandinavian Journal of Gastroenterology*. 2007; 42(2):171-178. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/17327936>; accessed 19 May 2008.
 50. Guttormsen V, Løvik A, Bye A, Bratlie J, Mørkrid L and Lundin KEA. No induction of anti-avenin IgA by oats in adult, diet-treated coeliac disease. *Scandinavian Journal of Gastroenterology*. 2008; 43(2):161-165. <http://www.informaworld.com/smpp/content~db=all?content=10.1080/00365520701832822>; accessed 10 Aug 2008.
 51. Dickey W. Making oats safer for patients with celiac disease. *Eur J Gastroenterol Hepatol* 2008, 20:494–495. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/18467905>; accessed 10 Aug 2008.
 52. Ellis HJ and Ciclitira PJ. Should coeliac sufferers be allowed their oats? *Eur J Gastroenterol Hepatol* 2008, 20:492–493. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/18467904>; accessed 10 Aug 2008.
 53. Hernando A, Mujico JR, Mena MC, Lombardia M, Mendez E. Measurement of wheat gluten and barley hordeins in contaminated oats from Europe, the United States and Canada. *Eur J Gastroenterol Hepatol* 2008; 20:545–554. Abstract available from: <http://www.ncbi.nlm.nih.gov/pubmed/18467914>; accessed 10 Aug 2008.
 54. Statistics Canada - Census 2006. Available from: <http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/hlt/97-550/Index.cfm?TPL=P1C&Page=RETR&LANG=Eng&T=101>; accessed 24 Aug 2009.