



# Dietitians in Gluten Intolerance Diseases (DIGID) Corner

*Amy Jones, MS, RD, LD*

(Author's Note: This is my last Dietitians in Gluten Intolerance Disorders (DIGID) corner. It has been a pleasure serving as chair of this subunit for the last 2 years. Our members are the most active registered dietitian nutritionist leaders in the gluten-free community. Our goal is always the evidence-based treatment of those who require the gluten-free diet. I am happy to turn the reins over to our new chair, Janelle Smith, who took over in June. I recently had the opportunity to spend a couple of days with Janelle at the Medical Nutrition Practice Group (MNPG) spring meeting, and I think you'll all be impressed with her knowledge, enthusiasm and forward thinking.)

## **A Conversation with Shelley Case, RD**

For over 25 years, Shelley Case has been one of the most prominent dietitian leaders in celiac disease and the gluten-free diet. Dietitians and other health professionals, celiac disease associations, food manufacturers and the government frequently look to Shelley for expert advice. I recently had an opportunity to speak with Shelley about how she became involved in the gluten-free world and her insight into some issues that dietitians and clients face.

### **AJ: Tell me a little bit about your background.**

SC: After I had received my Bachelor of Science degree in Nutrition and Dietetics from the University of Saskatchewan, I completed my dietetic internship at the Health Sciences Center in Winnipeg, Manitoba, Canada. My first job in

1982 was in an outpatient metabolic diabetes and diet education center where I was responsible for counseling not only adults and children with diabetes but those with other health issues such as allergies and celiac disease. I loved that job, but after 15 years I decided it was time for a change and opened my nutrition consulting business specializing in celiac disease and the gluten-free diet in 1997.

***AJ: Did you have a lot of experience in counseling patients with celiac disease in your first job?***

SC: Initially I felt very unprepared to counsel patients with celiac disease because the relevant information offered in only one nutrition class at university had been minimal, and I had never encountered anyone with this condition during the internship. Also, at that time there was no Google, so it was not easy to find practical information! However, I decided to reach out to the local celiac support group in Regina, Saskatchewan, for help. The chapter members taught me a lot about the disease and gluten-free diet. Shortly after, I was asked to be their chapter advisor. Then in 1995, I was invited to be on the Canadian Celiac Association Professional Advisory Board, a position I've held ever since.

While counseling clients it became apparent to me that there was a real need for more specific information about celiac disease and the gluten-free diet for consumers and health professionals. Thus, I decided to research and write a book on the subject. One of the numerous challenges in writing the book was deciding the target audience. Was it dietitians? Was it consumers? I eventually determined that the target audience should be consumers and health professionals. I originally planned to write it from just the Canadian perspective, but after talking with U.S. dietitians, they encouraged me to include American labeling regulations and other relevant information. After 2 long years of hard work, I self-published *Gluten-Free Diet: A Comprehensive Resource Guide* in 2001. Since then I have published four more editions for a total of 10 printings.

***AJ: In your view, what do you think are the biggest challenges facing those on the gluten-free diet?***

SC: There are many, and this would be the subject of a full newsletter! But what I see people struggle with the most is eating out and traveling. Trying to find safe restaurants or eating out when invited out by a friend, relative, colleague or at a social event is very challenging. Individuals worry about getting sick, so they always need to ask detailed questions about how foods are prepared and whether they have been cross-contaminated with gluten. Even when they try their best, it is still difficult, and mistakes can happen, resulting in various symptoms.

My husband and I recently returned from a European river cruise. Even though we had notified them a year in advance, the chef informed me that he had only been told the day before that he had five gluten-free guests. The number and variety of gluten-free bread and baked products was minimal and not the most appetizing. Plus, I ended up getting significant gut problems due to cross-contamination half way through the trip, putting a damper on our travels. Antidiarrheal medication and looking for the closest bathroom was always on my mind!

With the gluten-free fad, I have observed that many restaurants are not taking it as seriously as they should and are catering to those who do not have celiac disease. For example, I was at a restaurant that had a "gluten conscious lifestyle" menu that stated: "it is designed for lifestyle choice and not for allergies and is not gluten-free!" Issues like these create a great opportunity for dietitians to get involved in restaurant, college, hospital and other types of food service to improve gluten-free options that are prepared safely for customers and clients.

***AJ: What do you see as the biggest challenges facing dietitians working with gluten-free clients?***

SC: Dietitians often believe we can be all things to all people. However, a basic knowledge of celiac disease, gluten sensitivity and the gluten-free diet will not be that beneficial. Gluten-

related disorders, the gluten-free diet, ingredient production and labeling regulations are very complex, so the dietitian needs advanced training and expertise to educate clients effectively. If you're not up to speed, a client will see right through you. Several studies have evaluated the effectiveness of dietitians in instructing clients on the gluten-free diet, and the results have not been good. Over the years I have frequently heard from clients with celiac disease saying they knew more than the dietitian! That is why many DIGID colleagues and I have been passionate about educating dietitians and providing evidence-based, practical resources on the diagnosis and management of gluten-related disorders.

***AJ: How do you think Health Canada and Food and Drug Administration (FDA) gluten-free labeling regulations compare?***

SC: First it is important to understand which jurisdictions are responsible for regulating food and beverages. In Canada, food and alcoholic beverage regulations all fall under Health Canada's jurisdiction. However, it is more complicated in the United States because there are three departments involved in labeling, each with its own set of regulations and policy guidelines that often differ when it comes to gluten-free labeling. These departments include the FDA, US Department of Agriculture (USDA), and Alcohol and Tobacco Tax and Trade Bureau (TTB).

Health Canada Food and Drug Regulations require the 11 priority allergens and all gluten sources to be declared on the food label. In the United States, the top 8 allergens including wheat (but not barley or rye) must be listed as part of the Food Allergy Labeling and Consumer Protection Act (FALCPA). Although Health Canada and FDA have voluntary gluten-free labeling regulations with a 20 ppm gluten threshold, there are some differences. For example, the FDA allows four different gluten-free labeling terms ("gluten-free," "no gluten," "free of gluten," or "without gluten") whereas Health Canada only permits the term "gluten-free." Both countries include wheat, rye, and barley on their list of gluten-containing grains but Canada also includes oats on the prohibited list of grains. However, if oats are specially produced to ensure that they are under the 20 ppm they can be labeled "gluten-free."

***AJ: Oats continue to be a hot topic in the gluten-free world. What is your professional opinion on the safety of purity protocol versus mechanical/optical sorted oats?***

SC: Oats are frequently cross-contaminated with wheat, rye, and barley as demonstrated in studies from the United States, Canada and Europe. However, there are gluten-free oats available in the marketplace that can be produced by the purity protocol or by removing gluten from contaminated oats by mechanical/optical sorters. The vast majority of purity protocol oats are grown in Canada though there are a few U.S. producers. These companies go to great lengths to prevent cross-contact with gluten-containing grains. These include steps such as using pure seed for planting on land where no wheat, rye or barley has been grown for at least 3 to 5 years; field inspections; traceability records; dedicated or thoroughly cleaned equipment for seeding, harvesting, storage and transportation; extensive gluten testing; and milling in a dedicated gluten-free facility.

There are sophisticated mechanical and optical sorting technologies that can be used to separate wheat, rye and barley from contaminated oats. The type and quality of the sorting equipment as well as how it is operated can affect how much gluten-containing grain is removed. In spite of this technology, it is challenging to completely remove all of the whole and broken kernels of wheat, rye, and barley. This is particularly the case for barley kernels due to their similarity to oat kernels in size, shape, color and density. Also, this equipment is unable to remove gluten-contaminating dust from the oats. Thus there is a significantly higher risk of gluten contamination with oats produced under this method though it can vary from one miller to another depending on the equipment used, protocols and other factors.

Regardless of the methods used for producing gluten-free oats, it is critical that extensive gluten testing is undertaken. Also, adequate sampling protocols are essential to reduce the risk of missing any potential gluten contamination. DIGID member and gluten-free expert Tricia Thompson, RD, has written extensively on oat production methods, sampling protocols, testing methods



and the overall safety of this grain. For more information and various articles on this subject see <https://www.glutenfreewatchdog.org/news/category/gluten-free-oats/>

**AJ: This is the fifth edition of your book now entitled *Gluten Free: The Definitive Resource Guide*. What are some of the updates you included in this latest version?**

SC: I believe this is the best edition yet for many reasons. I'm thrilled that leading celiac medical expert Dr. Alessio Fasano has written the foreword. Also, based on feedback from dietitians and consumers, the information has been reorganized to make it even more user-friendly. The references and detailed technical information are now at the end of the book, so it does not overwhelm consumers. There are new chapters on oats and alcohol; gluten threshold levels/parts per million/testing; and frequently questioned ingredients. Extensively updated information about U.S. and Canadian gluten/allergen labeling has been added. There is more practical information about gluten-free alternatives; meal planning, shopping, cross-contamination, cooking/baking as well as new recipes; gluten-free products and manufacturer contacts; and evidence-based resources and references. You can learn more about this publication at [www.shelleycase.com](http://www.shelleycase.com)

**AJ: Thank you, Shelley, for sharing your journey and expertise on this important subject!**

#### *About the Author*

Amy Jones, MS, RD, LD, has been a registered dietitian for 16 years, working primarily in community hospitals. She has a special interest in celiac disease, and was the chair of the Dietitians in Gluten Intolerance Disorders, a subunit of the Medical Nutrition Practice Group, for the Academy of Nutrition and Dietetics. She founded and leads the Logan County Celiac Support group in Bellefontaine, Ohio. She is a preceptor for dietetic interns from Bowling Green State University, Bluffton University, and Rutgers University. She is a popular speaker, presenting regularly at regional and national celiac disease events. She is a frequent contributor to *Gluten Free Living* magazine and serves on the magazine's dietetic advisory board.

Amy holds a bachelor's degree in nutrition from West Virginia Wesleyan College, and a master's degree from Ball State University. She has also completed additional training in celiac disease at the University of Chicago.

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— NATIONAL BEST SELLER —

# Gluten Free

## The Definitive Resource Guide



- Safe foods & those to avoid
- Healthy gluten-free living tips
- Meal plans, recipes & cooking hints
- List of more than **3700** gluten-free foods
- Comprehensive directory of over **220** companies

**Shelley Case** **Dietitian**

**Foreword by Dr. Alessio Fasano**