

Celiac Disease—Patient Perspectives  
A presentation to  
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“In discussing digestive diseases from the patient’s perspective, I will be talking about celiac disease, which is my particular area of experience.

“Upon receiving a diagnosis of celiac disease, a patient is counseled by a medical professional that there is no medication and the only treatment is the strict adherence to a gluten-free diet for life. This means the complete avoidance of wheat, barley, rye and oats.

“At this point, the patient is faced with daily challenges which are often not understood by others. Wheat, barley, rye, and oats, are present in many foods, and are very often in forms not easily identifiable by the untrained individual.

“A trip to the grocery store is complicated because labels must be read and studied. Eating at a restaurant, going on vacation, taking prescription drugs (both generic and non-generic) becomes more challenging. Eating at school lunch programs or college cafeterias, going to the hospital as an inpatient for any reason, become more challenging. This also applies to going into a nursing home, or even going to a dentist. Use of cosmetics even becomes an issue.

“Without specialized knowledge, any or all of these occurrences could result in the ingestion of an offending grain and trigger a reaction. And the more often this happens, the more likely it is that the medical consequences will be more severe and/or long-term.

“The new patient can be truly overwhelmed with figuring out how to make a transition to the only diet for life that can keep them healthy.

“The Celiac Sprue Association (CSA) provides assistance to individuals through education and awareness with a personal touch. It is “Celiacs Helping Celiacs” and performs a vital role for individuals in need. CSA maintains a toll-free number, so help is only a phone call away. Callers can be referred to one of CSA’s 125 local support chapters and 62 resource units. The CSA website currently receives 3.4 million hits per month--another way that communication and sharing of information is fostered.

“CSA publishes and annually updates *The CSA Gluten-Free Product Listing* with name brand items whose ingredients have been verified by the manufacturers as gluten-free. *Celiac Disease: a Guide Through the Medicine Cabinet* and *The Directory of Drug Manufacturers* both by Marcia Milazzo, are also available to address the problem of hidden gluten in excipients, or fillers, in prescription drugs.

“CSA publishes a quarterly member newsletter, *Lifeline*. The association also holds an annual educational conference. This year it will be held in Tucson, Arizona from September 28<sup>th</sup> through September 30<sup>th</sup>. Attendees will be served gourmet meals that are free of wheat,

barley, rye and oats. They have the opportunity to share common interests and experiences, while attending sessions presented by leaders in the field of celiac disease. Cooking demonstrations and recipe sharing are also highlights.

“Many commercial food preparers are not aware, or misunderstand the health risk that exposure to wheat, barley, rye or oats presents to the celiac patient. CSA has helped raise awareness through providing restaurant cards explaining celiac dietary needs to restaurant staff.

“Looking to the future, one of our best hopes lies in research. Since celiac disease is currently the only autoimmune disease for which no medication is prescribed, it presents an ideal subject for study. Research on celiac disease could possibly lead to unlocking the key to other autoimmune diseases. While excipients in prescriptions remain a challenge, our hope is that informational inserts or labels will be included in or on the packaging for branded, generic and over-the-counter medications.

“The diagnosis of celiac disease is the vital first step in leading a healthy celiac lifestyle. Celiac disease has been termed “the great mimic”, since its many and varied symptoms are similar to other digestive and autoimmune diseases. Though studies indicate that 1 in 133 persons in the United States may have celiac disease, diagnosis has lagged behind this estimate. In the past, the average time from initial symptoms to diagnosis of celiac disease has been 11 years. By increasing physician and public awareness, the goal is to substantially shorten the period of time from presentation of symptoms to diagnosis.

As a member based organization, The Celiac Sprue Association stands poised to remain “Celiacs Helping Celiacs” through its mission of helping individuals with celiac disease and dermatitis herpetiformis worldwide through education, support and research.