18-1725

IN THE

United States Court of Appeals

FOR THE FOURTH CIRCUIT

J.D., by his father and next friend, Brian Doherty,

Plaintiff-Appellant,

—v.—

COLONIAL WILLIAMSBURG FOUNDATION,

Defendant-Appellee.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF VIRGINIA AT NEWPORT NEWS

BRIEF FOR *AMICI CURIAE* SCOTT HAYES AND VIRGINIA FOOD ALLERGY ADVOCATES (VFAA) IN SUPPORT OF PLAINTIFF-APPELLANT

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UNITED STATES COURT OF APPEALS FOR THE FOURTH CIRCUIT
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If yes, identify any publicly held member whose stock or equity value could be affected substantially by the outcome of the proceeding or whose claims the trade association is pursuing in a representative capacity, or state that there is no such member:

6. Does this case arise out of a bankruptcy proceeding? ☐ YES ☑ NO
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Signature: /s/ Theodore R. Debonis Date: September 26, 2018

Counsel for: Amicus

CERTIFICATE OF SERVICE

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I certify that on September 26, 2018 the foregoing document was served on all parties or their counsel of record through the CM/ECF system if they are registered users or, if they are not, by serving a true and correct copy at the addresses listed below:

/s/ Theodore R. Debonis (signature) September 26, 2018 (date)

Table of Contents

TABLE OF AUTHORITIES

Page(s)

Cases

Statutes

Other Authorities

STATEMENT OF INTEREST OF AMICI[1]

Amicus Virginia Food Allergy Advocates (VFAA) works with Virginia families to educate and support individuals with food allergies, celiac disease and eosinophilic esophagitis. VFAA works to educate local public and private schools on best practices for students with these disabilities. In 2015, VFAA worked to change food allergy guidelines in the Virginia Beach Public Schools so that all bus drivers received food allergy training to recognize the signs and symptoms of a severe allergic reaction and trained to administer epinephrine for students who self-carried it.

Amicus Scott Hayes uses his own experience in having celiac disease, as well as his research, to educate others about living with celiac disease. He has written a book, *From Crappy to Happy: The Naked Truth about Living with Celiac Disease*, and his blog, GlutenDude.com, is widely used by individuals with celiac disease. More than 33,000 comments have been posted on his blog to date.

[1] Pursuant to Federal Rule of Appellate Procedure 29(c)(4), *Amici* state that all parties have consented to the filing of this brief. Pursuant to Fed. R. App. P. 29(c)(5), *Amici* further state that (a) there is no party or counsel for a party in the pending appeal who authored this brief in whole or in part; (b) there is no party or counsel for a party in the pending appeal who contributed money that was intended to fund preparing or submitting the brief; and (c) no person or entity contributed money that was intended to fund preparing or submitting the brief, other than *Amici* and their members.

Amici submit this brief to provide the Court with information regarding the severity of some gluten-related disorders and food allergies, the inability of food service providers to sufficiently eliminate the risks of contamination of "safe" food for those with severe disabilities, and the anxieties suffered by these individuals when dining outside their homes. *Amici* strongly believe that individuals with severe food allergies should be able to enjoy places of public accommodation without advance notice like other customers and should not be expected to risk their health and safety when they require safe foods. *Amici* are deeply concerned that the district court decision will impede individuals whose disabilities require food restrictions from participating equally in society.

INTRODUCTION

Amici urge reversal of the district court's decision because the requested modification of allowing J.D. to eat food he and his family knew to be safe was necessary for him to fully and equally enjoy his school field trip to Colonial Williamsburg with his classmates without risking his health, and the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12101, does not require advance notice or inquiry into the facility's ability to provide the medically required diet. Because consumers like J.D. have good reason to be concerned that food service providers are unable to guarantee that their medically required dietary needs will be met, the

ADA requires that they must be provided with the accommodations and modifications necessary to ensure their own health.

Some individuals have such severe gluten-related dietary disabilities that they medically require elimination of even trace amounts of gluten from food they ingest because exposure can result in serious physical and mental consequences.[2] Exposure to gluten can cause severe gastrointestinal symptoms leading to malabsorption and malnutrition, as well as extra-intestinal symptoms like anemia, osteoporosis, and neurological problems. Gluten-related disorders can also have significant mental and emotional consequences, including anxiety and depression. There is no known cure for these disabilities; the only remedy is to avoid exposure through adoption of a gluten-free diet ("GFD").

But "gluten-free" means 100% gluten-free because even trace amounts can trigger symptoms. And 100% gluten-free can be difficult to maintain, particularly when individuals lack control over the food preparation process, as when they dine outside their homes. Commercial food service providers, even if they are aware of the risks and conscientious in their food preparation, are simply less prepared and less able to sustain the level of diligence required by their customers who medically require a gluten-free diet. Whether through inadvertent cross-contact or

[2] Jack A. Syage et al., *Determination of Gluten Consumption in Celiac Patients on a Gluten-Free Diet*, 107 Am. J. Clinical Nutrition 201 (2018).

carelessness, restaurants and other food service providers routinely expose their customers to unintended allergens such as gluten at levels that customers can, and must, avoid when they manage the food preparation process entirely on their own.[3]

The inability of food service providers to ensure their customers' medical needs exposes those customers to the physical risks of gluten exposure and increases the anxiety many already experience managing their disabilities in their day-to-day lives. Eating outside the home in restaurants, museums, theme parks, schools, and work is part of everyday life. For children, participation in overnight and all-day field trips entails eating outside their home and relying on the diligence of unknown food providers—unless they bring safe food from home with them. For teens, a severe gluten-related disorder or food allergy can be particularly difficult to incorporate into their lives because the inherent difficulties in following a GFD can have serious mental and emotional consequences.

Restaurants and other food service providers routinely advise customers with food allergies and sensitivities that they cannot guarantee no cross-contact. As a result, it is a reasonable modification to allow individuals who medically require gluten-free diets to bring safe food into places of public accommodation. *Amici* believe that the ADA does not require that individuals with severe disabilities rely

[3] Taylor J. Radke, et al., *Restaurant Food Allergy Practices – Six Selected Sites, United States, 2014*, 66 CDC Morbidity & Mortality Wkly. Rep. 404, 405-6 (2017).

on the representations of food service providers, particularly when those individuals have previously suffered serious harm from cross-contact or inadequate food safety precautions.

ARGUMENT

POINT I

INDIVIDUALS WITH SEVERE GLUTEN-RELATED DISORDERS REQUIRE ABSOLUTE DILIGENCE TO PROTECT THEIR HEALTH

A. Gluten-related disorders

"Gluten-related disorders" is an umbrella term for a range of diseases triggered by the ingestion of gluten. Although the mainstream public often refers to "gluten sensitivity" or "gluten intolerance" colloquially, the medical community has determined that broad labels are insufficient to acknowledge the unique characteristics and physiological responses of each and should be avoided.[4]

Gluten-related disorders can be grouped into three broad categories characterized by a person's response to gluten contact and the severity of the response: (1) autoimmune disorders, including celiac disease; (2) non-allergic, non-autoimmune, including non-celiac gluten sensitivity; and (3) wheat allergies.[5] In this brief, *Amici* refer to "gluten-related disorders" where appropriate to

[4] Jonas F. Ludvigsson et al., *The Oslo Definitions for Coeliac Disease and Related Terms*, 62 Gut 43 (2013).

[5] Anna Sapone et al. *Spectrum of Gluten-Related Disorders: Consensus on New Nomenclature and Classification*, 10 BMC Medicine 13, 13 (2012).

generalize across the spectrum of gluten-related disease and to individual disease where specificity is required. *Amici* outline for the Court why, for some individuals with severe disabilities, providing their own safe foods may be necessary given the level of diligence required to avoid even trace amounts of gluten and why, given the known food safety problems at restaurants, it is unreasonable to expect such individuals to trust commercial food providers to meet their needs for medically safe meals.

1. *Gluten*

Gluten is a family of water-insoluble plant proteins in grains and cereals.[6] People consuming a Western diet are most commonly exposed to gluten in wheat. Together with maize and rice, wheat is one of the three most important—and most consumed—crops in the world.[7] Wheat can be processed into a wide variety of foods due to the properties of gluten, which comprises 75%-85% of the total protein in wheat.[8] Gluten provides wheat viscoelasticity by forming a sticky, flexible network of proteins that binds the ingredients of dough like glue. It provides bread its chewy texture and gives wheat-based foods like pasta their shape.

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[6] Ludvigsson et al., 62 Gut at 45.

[7] Peter R. Shewry et al., *The Structure and Properties of Gluten: An Elastic Protein from Wheat Grain*, 357 Phil. Transactions Royal Soc'y London B Biologica Sci. 133, 133 (2002).

[8] *Id.*

2. *Celiac disease*

Celiac disease is a chronic autoimmune disorder triggered by gluten consumption that primarily affects the small intestine.[9] It is the most severe gluten-related disorder, and one of the most common inherited autoimmune disorders in the world, affecting approximately 1% of the population. Symptoms range from gastrointestinal distress and weight loss to osteoporosis and neurological problems.[10]

As an autoimmune disorder, celiac disease causes a person's body to react to gluten as a foreign agent, causing the immune system to attack the gluten and the lining of the intestinal track.[11] This damages the intestinal walls, causing nutritional deficiencies, digestive distress, and an increased risk of other, consequential disease.[12]

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[9] Benjamin Lebwohl, et al., *Celiac Disease and Non-Celiac Gluten Sensitivity*, 351 BMJ (Oct. 5, 2015), at 1, *available at* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4596973/?report=printable.

[10] Naiyana Gujral, Hugh J. Freeman and Alan BR Tomson, *Celiac disease: Prevalence, Diagnosis, Pathogenesis, and Treatment*, 18 World J. Gastroenterology 6036 (2012).

[11] *Id.* at 6036.

[12] *Id.* at 6036-37.

Celiac disease is usually diagnosed by blood test, with confirmation by biopsy of the small intestine.[13] Currently, the only available medical treatment for people with celiac disease is a lifelong gluten-free diet.

3. *Non-celiac gluten sensitivity*

Many people who suffer negative effects from ingesting gluten do not test positive for celiac disease but nonetheless have similar symptomatic reactions.[14] This condition, called non-celiac gluten sensitivity ("NCGS"), is essentially the default medical diagnosis when celiac disease and wheat allergy are excluded. Unlike celiac disease, there is no identifiable biomarker available for diagnosing NCGS. As a result, people who suffer from NCGS often endure long histories of health complaints, inconclusive medical diagnoses, and untreated gastrointestinal and extra-intestinal complications. With adolescents like J.D., the medical community often experiences particular difficulty determining whether a patient has celiac disease or NCGS.

Patients who suffer from NCGS experience many of the same symptoms as celiac disease patients: gastrointestinal pain, bloating, nausea, gastroesophageal

[13] *Id.* at 6037.

[14] Lebwohl et al., 351 BMJ, at 9; Pasquale Mansueto et al., *Non-Celiac Gluten Sensitivity: Literature Review*, 33 J. Am. C. Nutrition 39 (2014).

reflux disease,[15]and diarrhea. They can also experience extra-intestinal symptoms with no associated gastrointestinal factors: headache, fatigue, muscle pain, extremity numbness, and dermatitis. Finally, they can suffer anxiety, depression and neuropsychiatric disorder like autism, schizophrenia, and attention deficit hyperactivity disorder.[16] There is no known treatment for NCGS other than a GFD.

4. *Wheat allergy*

Some individuals experience an adverse reaction to gluten as a result of wheat allergy. About 1% of the population suffers from this gluten-related disorder that is unrelated to either celiac disease or NCGS but has similar gastrointestinal symptoms. However, wheat allergy has a much faster onset of symptoms—often as little as a few minutes—compared to celiac disease and NCGS. Wheat allergy can also result in anaphylaxis, which occurs when a release of chemicals in response to the exposure to an allergen causes a life-threatening reaction. Like celiac disease and NCGS, the only treatment for wheat allergy is a strict GFD.

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[15] Gastroesophageal reflux disease occurs when stomach acid frequently flows back into the tube connecting your mouth and stomach (esophagus). This backwash (acid reflux) can irritate the lining of the esophagus. *See* *https://www.mayoclinic.org/diseases-conditions/gerd/symptoms-causes/syc-20361940*.

[16] Lebwhohl et al., 351 BMJ, at 10.

B. The gluten-free diet

A strict gluten-free diet is the only remedy available for an individual who suffers from severe gluten-related disorder. A GFD excludes gluten, the proteins present in wheat, barley, rye, and all derivatives of these grains, and the foods that contain them. Oats and other grains are often excluded from a gluten-free-diet due to the potential for cross-contact from other grains or cereals during harvesting, transportation, storing, processing, handling and cooking.

A GFD is challenging because it not only requires lifestyle modifications, but it also requires strict diligence in identifying sources of gluten exposure and avoiding cross-contact. Living with severe gluten-related disorder remains difficult "primarily due to concerns of cross-contact of foods with gluten even in establishments where there are gluten-free options."[17] Even trace amounts of gluten can be harmful to patients with severe gluten-related disorder.[18]

[17] Julia Bandini, *Is It Just Food?: The Social Implications of Celiac Disease as a Disability,* 30 Disability & Society, 1577, 1578 (2015).

[18] Carlo Catassi et al., *A Prospective, Double Blind, Placebo Controlled Trial to Establish a Safe Gluten Threshold for Patients with Celiac Disease.* 85 Am. J. Clinical Nutrition, 160, 165 (2007).

POINT II

GLUTEN EXPOSURE HAS SEVERE CONSEQUENCES AND IS DIFFICULT TO AVOID

A. The physical consequences of gluten exposure can be severely harmful for individuals with disabilities

People who suffer from celiac disease and other severe gluten-related disorders experience a wide range of negative effects from ingesting gluten: gastrointestinal symptoms, extra-intestinal symptoms, or no symptoms at all. Classic gastrointestinal symptoms include diarrhea, bloating, loss of appetite, impaired growth, steatorrhea,[19] and weight loss due to malabsorption of nutrients by the small intestine. However, some people with celiac disease, in particular, do not have any digestive symptoms but instead only suffer from symptoms typically associated with other diseases. About 50% of severe gluten-related disorder patients present extra-intestinal symptoms: anemia, osteoporosis, dermatitis herpetiformis,[20] neurological problems, and dental enamel hydroplasia. The widely variable clinical picture is due to the genetic and immunological bases of

[19] Excessive fat in stools caused by malabsorption by the small intestine. *Steatorrhea*, Merriam-Webster Dictionary (2018), https://www.merriam-webster.com/dictionary/steatorrhea.

[20] Dermatitis herpetiformisis a chronic skin condition caused by a reaction to gluten ingestion. Most patients with DH also have an associated gluten sensitive enteropathy (celiac disease). Extremely itchy bumps or blisters appear on both sides of the body, most often on the forearms near the elbows, as well as on knees and buttocks, and along the hairline. *See* Celiac Disease Foundation, https://celiac.org/celiac-disease/understanding-celiac-disease-2/dermatitis-herpetiformis/#PRyBgkkeAVaDLV36.99 (last visited September 26, 2018).

the diseases, with various factors including age of onset, extent of mucosal injury, dietary habits, and gender, all affecting its progression.[21]

Individuals with celiac disease face a significantly increased risk of certain types of cancers—including small intestinal cancer—especially if a strict GFD is not followed or in adults who are undiagnosed for an extended period of time.[22] A large population-based study obtained over four decades found that individuals with confirmed celiac disease had an overall 5.4-fold increased risk of developing Non-Hodgkin Lymphoma, a fatal cancer in which white blood cells develop abnormally.[23] Celiac disease may also develop into Enteropathy-associated T-cell lymphoma (EATL), a rare type of non-Hodgkin lymphoma with a high mortality rate.[24]

B. The psychological consequences of gluten exposure can be severely harmful for individuals with disabilities

There is a demonstrated correlation between gluten-related disorder, continued gluten exposure, and psychiatric and emotional difficulties. A review of

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[21] Gujral et al., 18 World J. Gastroenterology, at 6037.

[22] Sonia Kupfer, *Risk of Gastrointestinal Cancer in Celiac Disease*, Impact (Univ. of Chicago Medicine, Celiac Disease Center, Chicago, Ill.) Oct. 2016, at 1.

[23] Ying Gao et al., *Increased Risk for Non-Hodgkin Lymphoma in Individuals with Celiac Disease and a Potential Familial Association*, 136 Gastroenterology 91, 94 (2009).

[24] A. Al-toma et al., *Survival in Refractory Coeliac Disease and Enteropathy-Associated T-cell Lymphoma: Retrospective Evaluation of Single-Centre Experience*, 56 Gut 1373 (2007).

all studies available from 1900 until 2014 concluded that: "Celiac disease has a considerable psychological impact. Some elements of this may relate to the disease and its biochemical effects, but other aspects relate to the patient's subjective perception of the disorder and of the GFD used to treat it."[25]

This same review showed that anxiety and depression are two of the primary diagnoses that have been widely described in celiac disease patients.[26] A study of children with celiac disease concluded that celiac disease impaired quality of life by decreasing functionality in social relations, emotional life, and physical health. It also found that at least one psychiatric diagnosis was present in half of the cases.[27] Furthermore, "the adolescents who did not adhere [to the] diet had worse quality of life; they felt sick, had more psychiatric problems, and had more problems in school."[28]

C. Avoiding gluten is extremely difficult

Although strict adherence to a GFD is the only effective and safe treatment of severe gluten-related disorders, it can be very difficult to completely avoid

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[25] Fabiana Zingone et al., *Psychological Morbidity of Celiac Disease: A Review of the Literature,* 3 United Eur. Gastroenterology J. 136, 141 (2015).

[26] *Id.* at 138.

[27] Eylem Sevinç et al., *Psychopathology, Quality of Life, and Related Factors in Children with Celiac Disease,* 93 J. Pediatria (Rio J). 267, 271 (2017).

[28] *Id.*

gluten, due to cross-contact of food products, and the wide variety of food products that contain gluten, often as a hidden ingredient.

1. *Patients following a GFD are still routinely exposed to gluten*

Several recent studies have shown that many patients trying to follow a strict GFD are still exposed to measurable amounts of gluten. One study analyzed waste samples of celiac patients adhering to a GFD. The authors concluded that, "many individuals following a GFD regularly consume sufficient gluten to trigger symptoms and perpetuate intestinal histologic damage."[29] The authors further concluded that, because the gluten-free diet "is vulnerable to gluten exposure" and "continued exposure leads to persistent histologic injury and episodic symptom distress in celiac disease patients following a GFD," there is a need for "drug development for this autoimmune disease, for which no effective drug therapy exists."[30]

Another study showed that over 45% of the children and 48% of the adults on a long-term GFD tested were exposed to measurable amounts of gluten.[31] A third study, known as the "Doggie Bag" study, analyzed both waste samples from a population of celiac patients adhering to a gluten-free diet, and samples of the food

[29] Syage et al., 107 Am. J. Clinical Nutrition, at 201.

[30] *Id.* at 206.

[31] María de Lourdes Moreno et al., *Detection of Gluten Immunogenic Peptides in the Urine of Patients with Coeliac Disease Reveals Transgressions in the Gluten-Free Diet and Incomplete Mucosal Healing*, 66 Gut 250, 254 (2017).

eaten by the patients during the study.[32] The researchers found that 66% of the patients were exposed to measurable amounts of gluten.[33] Finally, in a survey of patients newly diagnosed with celiac disease, 72% of the participants self-reported "having had a reaction to gluten" while trying to follow a GFD.[34] Of those, 30% reported that the amount of gluten consumed to trigger their reaction resulted from cross-contact.[35]

2. *Cross-contact and hidden gluten are pervasive problems for maintaining a GFD*

Cross-contact (also referred to as cross-contamination) occurs when a gluten-free food or food product is exposed to a gluten-containing ingredient, making it unsafe for a person with a gluten-related disorder to consume. Cross-contact can arise from a variety of sources, during any stage of food preparation, from harvesting raw foods through serving the finished product.

Cross-contact can occur when restaurant staff is unaware of gluten as an ingredient in processed food or the diligence required to avoid cross-contact. It

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[32] Amy Ratner, *Celiac Disease Researchers Examine the Content of Patients' Doggie Bags*, Beyond Celiac (June 15, 2018), *available at* http://www.beyondceliac.org/research-news/View-Researc-News/1394/postid--110252/.

[33] *Id.*

[34] Jocelyn A. Silvester, et al., *Symptomatic Suspected Gluten Exposure is Common Among Patients with Coeliac Disease on a Gluten-Free Diet*, 44 Alimentary Pharmacology & Therapeutics 612, 615 (2016).

[35] *Id.*

frequently occurs during efforts to prepare and cook gluten-free meals because avoiding contamination requires precision in separating gluten-free from gluten-containing kitchen utensils, pots, pans, prep area (including cutting boards, mixing bowls, and food-storage containers), and equipment (including mixers, toasters, convection ovens, grills, and fryers).

Cross-contact can also occur during food handling and delivery. For example, cross-contact can result if an employee does not put on a fresh apron or fresh gloves before preparing gluten-free meals, or if a server spills any gluten-containing ingredients (such as salad croutons or certain salad dressings) onto the plate of a gluten-free meal. Cross-contact can occur in the production or packaging line, when gluten-free products share the same facilities and/or equipment with gluten-containing products, and the equipment is not properly cleaned between production runs. For that reason, pre-packaged products often bear cross-contact warnings stating that a product was made in "a facility that also processes wheat."

Some gluten contamination can also come from products inaccurately labeled as "gluten-free." In the United States, the label "gluten free" does not mean that the food is 100% gluten free.[36] In August 2013, the FDA issued a rule

[36] Internationally, gluten-free labeling standards follow the United Nations Codex Alimentarius Standard 118-1979, which recommends good manufacturing

providing that, for any packaged food or food product (including dietary supplements) to be labeled "gluten-free," the product must contain less than 20 ppm (mg/kg) of gluten.[37] However, testing for that threshold, along with the labeling rule itself, is voluntary, and manufacturers can face regulatory action only if their products bearing "gluten-free" labels are found to have more than 20 ppm of gluten. While the rule applies only to FDA-regulated packaged food products, the FDA has said that restaurants should be consistent with the FDA's definition when making "gluten-free" claims on their menus.[38]

Exposure to gluten can also result from unexpected food items, like sausages, imitation meats, soups, soy sauces, or ice cream. Even some foods that otherwise are inherently gluten-free have been found to contain significant amounts of gluten. In a 2010 study testing 22 single-ingredient, inherently gluten-free items, over 30% of the products tested were found to contain greater than 20ppm gluten, and one product contained 2,925 ppm of gluten.[39] Thus, those

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practices to prevent cross-contact. In Australia and New Zealand, legislation is stricter: gluten-free food must not contain any detectable gluten.

[37] Food Labeling; Gluten-Free Labeling of Foods, 78 Fed. Reg. 47,154 (Aug. 5, 2013), *codified at* 21 C.F.R. § 101.91

[38] *Questions and Answers: Gluten-Free Food Labeling Final Rule*, U.S. Food & Drug Admin., *available at* https://www.fda.gov/Food/GuidanceRegulation/GuidanceDocumentsRegulatoryInformation/Allergens/ucm362880.htm.

[39] Tricia Thompson et al., *Gluten Contamination of Grains, Seeds, and Flours in the United States: A Pilot Study*, 110 J. Am. Dietetic Ass'n 937, 938-39 (2010).

preparing gluten-free foods must thoroughly understand all of a recipe's ingredients to avoid potential contamination.

POINT III

INDIVIDUALS WITH GLUTEN DISORDER MUST EXERCISE A HIGH DEGREE OF CAUTION WHEN EATING OUT

Eating outside their home can be very risky for individuals with medically restricted diets because commercial food providers often do not adhere to the protocols required for food safety for individuals. Observational studies have shown significant problems with adherence to food safety rules. In 2005, the Centers for Disease Control and Prevention's Environmental Health Specialists Network found that most restaurant workers fail to wear gloves when touching ready-to-eat food and routinely demonstrated other unsafe practices.[40] A 2018 review of published research showed "[s]tudies that measured the identification of food allergens on menus and other documentation through in-person observations (compared to participant self-reporting) reported a lower use of this practice."[41] This finding corroborates previous research that found that "food service staff tend

[40] Laura Green et al., *Food Service Workers' Self-Reported Food Preparation Practices: An EHS-NET Study*, 208 Int. J. Hygiene Envtl. Health 27 (2005).

[41] Ian Young & Abhinand Thaivalappil, *A Systematic Review and Meta-Regression of the Knowledge, Practices, and Training of Restaurant and Food Service Personnel Toward Food Allergies and Celiac Disease*, 13 PLOS One e0203496, at 14, *available at* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6122805/pdf/pone.0203496.pdf.

to overestimate their safe food handling practices on self-report surveys."[42] Several studies have also shown that, while restaurant managers and staff generally believe that restaurant employees should be knowledgeable about food allergies, less than half had actually received training regarding food allergies.[43] One concluded that "[a]t restaurants the majority of the informants always asked about the food content but often the staff was ignorant of hypersensitivity to gluten. At times the informants had to enter into disputes with the staff in order to get proper food."[44] As a result, "[p]roblems ordering in restaurants contributed to 30% of suspected gluten exposures," primarily because "[a]wareness of the intricacies of a gluten-free diet is sub-optimal, even among chefs and food industry workers."[45]

In a survey of restaurant personnel, 78% of restaurant managers reported that their restaurants did not have a dedicated set of utensils or equipment for making allergen-free food, and only 7.6% of managers reported that their restaurant had a special area in the kitchen for allergen-free food preparation.[46]

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[42] *Id.*

[43] *Id.* at 6, 11; Taylor J. Radke, et al., *Food Allergy Knowledge and Attitudes of Restaurant Managers and Staff: An EHS-Net Study*, 79 J. Food Prot. 1588 (2016), *available at* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5321626/.

[44] Annette Sverker et al., *'Controlled by Food'– Lived Experiences of Coeliac Disease*, 18 J. Hum. Nutrition & Dietetics 171, 171 (2005).

[45] Silvester et al., 44 Alimentary Pharmacology & Therapeutics, at 615.

[46] Taylor J. Radke, et al., *Restaurant Food Allergy Practices – Six Selected Sites, United States, 2014*, 66 CDC Morbidity & Mortality Wkly. Rep. 404, 405 (2017).

The results for individuals who require medically restricted diets are serious and sometimes fatal. One study found that approximately one-third of food allergic individuals reported experiencing at least one allergic reaction due to eating at restaurants.[47] A 2018 review found that "63 deaths were identified from 1994-2006 in a voluntary registry of food-induced anaphylaxis fatalities, and nearly half of these deaths (46%) were caused by food exposure at a restaurant or other food service establishment."[48]

Because it is so difficult to guarantee the absence of cross-contact and hidden allergens or gluten, it is necessary for individuals who require a 100% GFD like J.D. to be allowed the modification of bringing and eating home-prepared food, known to be safe, while participating in a school's field trip.

POINT IV

CHILDREN WITH GLUTEN DISORDER AND SEVERE ALLERGIES FIND EATING OUT HIGHLY STRESSFUL

Children with celiac disease, severe gluten intolerance, or severe food allergies face a daily, two-pronged battle. These children have to face the typical social stressors of childhood in combination with the additional difficulties

[47] N. Wanich et al., Abstract, *Food Allergic Consumer (FAC) Experience in Restaurants and Food Establishments*, 121 J. Allergy & Clinical Immunology S182, S182 (2008).

[48] Ian Young & Abhinand Thaivalappil, 13 PLOS One e0203496, at 2. *See also* National Food Allergy Death Registry, *available at* https://www.nationalfoodallergydeathregistry.org/the-registry.

inherent in following a strict GFD. Dr. Alessio Fasano, one of the leading celiac experts in the world, explains that for individuals with celiac disease "one of the most natural [things] to humankind, eating, will become a very challenging mental exercise rather than a very spontaneous activity."[49] The hyper vigilance and daily management that are necessary when an individual has a severe food allergy can have a profound psychosocial impact on children, adolescents, and their families.[50] Even those who follow a GFD for an extended period of time find that eating out in situations where their food is not self-prepared will lead to increased worry. A study of those following a GFD for over five years found that the study's subjects were still plagued by concerns over "limited food choices in restaurants, cafeterias, hospitals and nursing homes, as well as worry about the safety of foods in these establishments."[51]

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[49] *The Demonization of Gluten*, Freakonomics Radio (Oct. 18, 2017), *available at* http://freakonomics.com/podcast/demonization-gluten/.

[50] A.J. Cummings et al., *The Psychosocial Impact of Food Allergy and Food Hypersensitivity in Children, Adolescents and Their Families: A Review*, 65 Allergy, 933, 943 (2010) ("It is evident that food allergy has a profound psychosocial impact on children, adolescents and their families. In particular, the constant vigilance needed to avoid allergens and the daily management of food allergy impacts on daily family activities and social events. Food allergy also appears to have a considerable detrimental effect on certain aspects of QoL such as emotional QoL, physical functioning and quality of school life.").

[51] Marion Zarkadas et al., *Living with Coeliac Disease and a Gluten-Free Diet: A Canadian Perspective*, 26 J. Hum. Nutrition & Dietetics 10, 19 (2013).

Numerous studies have shown that children experience shame in following a GFD.[52] Children with celiac disease find eating outing out highly stressful and many choose to avoid eating out or bring their own food in order to ensure safe eating. A study of children under 16 years old with biopsy-confirmed celiac disease found a clear aversion to restaurants and also found that the vast majority of children always traveled with their own food: "[r]estaurants were avoided all or most of the time by 54%. . . .[A]nd during travel, 83% brought gluten-free food with them all of the time."[53]

Children following a GFD find themselves stressed and isolated as a result of following the GFD that is necessary to maintain their health. A Canadian Celiac Association Health Survey of 2618 adults and 168 children with biopsy-confirmed celiac disease demonstrated the pervasive concerns encountered in maintaining a GFD:

> [C]hildren and their families had difficulty determining whether foods were GF (92%) and finding GF foods (90%), as well as avoiding restaurants (95%) and traveling (46%) all or some of the time. Children with Celiac Disease were angry about having to follow a

[52] "Consistent with other studies, we found that children often felt isolated or different on account of their need to eat different food." Gonzalo Bacigalupe & Aleksandra Plocha (2015). Celiac is a social disease: Family challenges and strategies. Families, Systems, & Health, 33(1), 46-54 *available at* http://dx.doi.org/10.1037/fsh0000099.

[53] Mohsin Rashid et al., *Celiac Disease: Evaluation of the Diagnosis and Dietary Compliance in Canadian Children*, 116 Pediatrics e754, e756 (2005), *available at* http://pediatrics.aappublications.org/content/pediatrics/116/6/e754.full.pdf.

> special diet (72%), felt different from other children (69%), were left out of activities at school or friends' homes (61%), and were embarrassed to bring GF foods to parties (53%) all or some of the time.[54]

A study of families with children between the ages of six and twelve with celiac disease found that the primary coping strategy employed to take care of their need for a GFD was to plan ahead and bring gluten-free food when eating outside the home. "The primary strategies cited by participants in this study for managing the GFD included planning ahead and bringing food to social functions."[55] In light of the widespread stress experienced by children in following a GFD when outside the home and the significant risk to their health, the importance of allowing children to bring their own food to a restaurant is a reasonable modification as required by the ADA.

POINT V

THE ADA REQUIRES THAT PLACES OF PUBLIC ACCOMMODATION PROVIDE REASONABLE MODIFICATIONS FOR INDIVIDUALS WITH DISABILITIES THAT REQUIRE A MEDICALLY RESTRICTED DIET

The broad framework of the ADA requires the provision of reasonable modifications for individuals who otherwise cannot avail themselves of equal access because of their disabilities. The ADA defines a disability as "a physical or

[54] Shelley Case, *The Gluten-Free Diet: How to Provide Effective Education and Resources*. 128 Gastroenterology S128, S128 (2005).

[55] Gonzalo Bacigalupe & Aleksandra Plocha (2015). Celiac is a social disease: Family challenges and strategies. Families, Systems, & Health, 33(1), 46-54 available at http://dx.doi.org/10.1037/fsh0000099.

mental impairment that substantially limits a major life activity."[56] The ability to eat food in order to nourish and sustain one's body is critical to one's health and well-being. Eating is explicitly defined as a "major life activity" under the law.[57] Under the ADA, a "restaurant, bar, or other establishment serving food or drink," a "museum", and "an amusement park or other place of recreation," are all considered to be places of public accommodation.[58]

Restaurants have been held accountable by appeals courts for violating the ADA by not allowed customers with disabilities to have the same experience as that provided for non-disabled patrons.[59] The Eleventh Circuit recently held that a blind plaintiff had submitted a plausible claim for relief under the ADA when a restaurant failed to offer blind individuals access to its website. "It appears that the website is a service that facilitates the use of Dunkin' Donuts' shops, which are places of public accommodation. And the ADA is clear that whatever goods and services Dunkin' Donuts offers as a part of its place of public accommodation, it

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[56] 42 U.S.C. § 12102 (1)(A), (H) & (I).

[57] "[M]ajor life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working." 42 U.S.C. § 12102 (2)(A).

[58] 42 U.S.C. § 12181(7)(B).

[59] *Antoninetti v. Chipotle Mexican Grill, Inc.*, 643 F.3d 1165, 1173- 74 (9th Cir. 2010); *see Haynes v. Dunkin' Donuts LLC*, No. 18-10373, 2018 WL 3634720 (11th Cir. July 31, 2018).

cannot discriminate against people on the basis of a disability, even if those goods and services are intangible."[60]

The ADA extends to individuals whose disabilities require medically restricted diets. The 2012 Lesley University Settlement Agreement marked the first time that the Justice Department extended the protections of the ADA to severe food allergies, and specifically to celiac disease. The DOJ's settlement with the private Lesley University was made in response to a complaint brought by students with celiac disease and severe food allergies alleging that they could not fully and equally enjoy the university's meal plan and food services in compliance with the ADA.[61] Under the settlement, the university agreed to provide gluten-free options in its dining hall, provide a dedicated space in its main dining hall to store and prepare gluten-free and allergen-free foods and to avoid cross-contact, to train food services personnel in identifying food allergens, and to pay $50,000 in compensatory damages, among a variety of remedies.[62]

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[60] *Haynes v. Dunkin' Donuts LLC*, No. 18-10373, 2018 WL 3634720, at *2 (11th Cir. July 31, 2018).

[61] Press Release, *Justice Department and Lesley University Sign Agreement to Ensure Meal Plan is Inclusive of Students with Celiac Disease and Food Allergies*, (Dec. 20, 2012) U.S. Dep't of Justice, *available at* https://www.justice.gov/opa/pr/justice-department-and-lesley-university-sign-agreement-ensure-meal-plan-inclusive-students.

[62] Settlement Agreement Between the United States of America and Lesley University, (Dec. 20, 2012), U.S. Dep't of Justice, *available at* https://www.justice.gov/iso/opa/resources/759201212201614325038 26.pdf.

Still, issues with providing food accommodation in educational settings persist. In 2016, the New England Celiac Organization (NECO) conducted a survey of college students living with gluten-related disorders and found 44% of the students surveyed by NECO said that their trouble with getting safe food persisted for their entire time at the university and 30% reported that they have absolutely no solutions for their dietary needs.[63] Preliminary 2016 Beyond Celiac college student survey results showed that 30% reported missing class due to gluten exposure.[64] "Diet adherence appeared to be most challenging in the social realm, where a patient must self-identify and/or rely upon others, such as when ordering at a restaurant or eating at another person's home."[65]

As noted above, there is a wide spectrum of gluten-related diseases, and there are some individuals whose disabilities are so severe that even trace amounts of gluten can cause severe physical and psychological harms. For such individuals, it is necessary to bring medically-safe food to a living history museum like Colonial Williamsburg so that they can have "full and equal enjoyment" of the

[63] *College Students with Celiac Disease Don't Have Access to the Gluten-Free Food They Need*, Beyond Celiac (Aug. 23, 2016), *available at* https://www.beyondceliac.org/celiac-disease-news/Celiac-Disease-in-the-News-article/1395/postid--53001/.

[64] *Serving Gluten-Free Students: Two Surveys Find America's Colleges Still Need Better Solutions*, Beyond Celiac, *available at* https://www.beyondceliac.org/SiteData/docs/NECOgraphi/aba42d21e33764d7/NECO%20graphic.pdf.

[65] Silvester et al., 44 Alimentary Pharmacology & Therapeutics, at 617.

place of public accommodation. 42 U.S.C. § 12182(a). Individuals without disabilities were not required to plan in advance for their participation in the Tavern's program; therefore, requiring the individual with a disability to provide advance notice and conduct an investigation of the facility's capacity to provide a gluten-free meal days before arriving, would impose a heavy burden on such individuals and deny them "full and equal enjoyment." *See A.L. v. Walt Disney Parks & Resorts. U.S., Inc.*, 900 F.3d 1270, 1294 (11th Cir. 2018) (holding that genuine issues of material fact existed as to whether the Disney's ride pass system for disabled children provided a like experience as to that of non-disabled children, taking into account the needs of specific disabilities).

For a student on a field trip with a tight schedule, participating in the Tavern's entertainment without eating would not have been "full and equal enjoyment" when all the student's peers were able to eat there and then pursue the other field trip activities. And eating food prepared by a commercial provider is not a viable option for a student who had already suffered serious physical consequences from eating food that other commercial providers had assured him would be "gluten-safe." Thus, allowing J.D. to eat his safe meal was a necessary and reasonable modification required by the ADA, and the district court's decision should be reversed.

CONCLUSION

For the reasons stated above, this Court should reverse the district court decision and remand the case for further proceedings.

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CERTIFICATE OF COMPLIANCE

This brief complies with the type-volume limitation of Fed. R. App. P. 29(d) and 32(a)(7)(B) because it contains 6,075 words, excluding the parts of the brief exempted by Fed. R. App. P. 32(a)(7)(B)(iii).

This brief complies with the typeface requirements of Fed. R. App. P. 32(a)(5) and the type style requirements of Fed. R. App. P. 32(a)(6), as it has been prepared in a 14-point, proportionally spaced typeface, Times New Roman, by using Microsoft Word 2007.

Dated: September 26, 2018

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CERTIFICATE OF SERVICE

I hereby certify that this brief has been served through the Court's ECF system on counsel for all parties required to be served on September 26, 2018.

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