

Voluntary Recommendations for

# MANAGING CELIAC DISEASE IN LEARNING ENVIRONMENTS



# TABLE OF CONTENTS:

<b>Foreword</b> .....	<b>1</b>	<b>Putting Recommendations into Practice</b> .....	<b>23</b>
<b>Acknowledgements</b> .....	<b>2</b>	School Boards and District Staff .....	24
<b>Introduction</b> .....	<b>4</b>	School Administrators, Staff, and Other Personnel.....	25
Overview and Purpose		· Principals and School Administrators	
Methods		· Classroom Teachers and Teaching Assistants	
<b>About Celiac Disease</b> .....	<b>9</b>	· School Nurses	
· Celiac Disease Overview		· School Psychologists and Counselors	
· Gluten-Free Diet 101		· School Food Service Managers and Staff	
· Impact on Learning		· Facilities and Maintenance Staff	
· Physical Symptoms that Disrupt Learning		<b>Parents/Guardians and Families</b> .....	<b>34</b>
· Exclusion and Isolation		· Parents of Children with Celiac Disease	
· Bullying and Discrimination		· Parent Teacher Associations	
· Risks for Gluten Exposure		<b>Children with Celiac Disease</b> .....	<b>36</b>
<b>Important Relevant Research</b> .....	<b>11</b>	· Teens with Celiac Disease	
<b>Federal Laws and Regulations that Govern Celiac Disease in Learning Environments</b> .....	<b>14</b>	· Children Ages 7-12	
· Section 504 of the Rehabilitation Act		· Children Ages 3-6	
· Americans with Disabilities Act		<b>Physicians, Nurses, Psychologists and Other Health Professionals</b> .....	<b>38</b>
· Gluten-Free Food Labeling Law		<b>Resource Documents</b> .....	<b>39</b>
· National School Lunch Act		· Sample Diagnosis Letters for Schools	
· Child Nutrition		· Gluten-Free Safe, Unsafe, and Questionable Foods List	
<b>The Celiac Disease Management Plan (CDMP)</b> .....	<b>16</b>	· Gluten-Free Tips for the Cafeteria	
· Formal Professional Development on Celiac Disease for Personnel Working with Children with Celiac Disease in Learning Environments		· Preventing Cross-Contact of GF Foods	
· Educating Children and Family Members About Celiac Disease		· Gluten-Free Flours and Grains Guide	
· Ensuring the Daily Management of Celiac Disease for Individual Children by Creating an Inclusive and Safe Learning Environment		· Simple Classroom Substitutions	
· Developing a Plan for Gluten Exposures		· Home Economics and Cooking Class Modifications	
		· Gluten-Free School Supply List	
		· Sample Letter Explaining Celiac Disease to Class Parents	
		· Gluten-Free Ingredients Glossary	

# FOREWORD

Celiac disease is a common autoimmune condition that affects approximately 1 percent of children in the United States, most of whom attend federal- and state-supported learning programs every weekday. When patients with celiac disease eat gluten (a protein found in wheat, rye, and barley), this stimulates the immune system leading to inflammation and damage to the nutrient-absorbing villi in the small intestine. Both inflammation and malnutrition caused by celiac disease can lead to severe limitations of bodily function and complications that have significant effects on children and their families, as well as on the learning institution they attend.

In addition to food, gluten is found in many everyday supplies used in learning environments. Inadvertent or accidental ingestion of gluten affects the ability of a student with celiac disease to learn and seriously endangers their health, both immediately and in the long term. Additionally, some children with celiac disease face health challenges related to celiac disease and its management that affect their social and emotional development.

Currently, there is no cure for celiac disease, so the treatment is a strict gluten-free diet. Working together with families and medical providers, staff in learning environments can take steps to protect children with celiac disease when they are not in the direct care of their parents or family members. When a plan is in place to support a child with celiac disease, institutions are removing barriers and helping children achieve their full academic, social, and emotional potential.

These recommendations advocate developing a **Celiac Disease Management Plan (CDMP)** for children with celiac disease. A successful plan depends on a strong partnership among families, medical practitioners, and staff in learning environments to help children overcome challenges associated with having celiac disease. Learning environments that implement a CDMP are responsive to the needs of children with celiac disease in their community and are poised to help each child to succeed and thrive in his or her individual environment.

We sincerely thank you for taking the time to use these materials to help children living with celiac disease participate in all learning activities and realize their full potential.

Sincerely,



*Vanessa M. Weisbrod*

Vanessa Weisbrod  
Executive Director  
Celiac Disease Program,  
Children's National Hospital



*Marilyn G. Geller*

Marilyn G. Geller  
Chief Executive  
Celiac Disease Foundation

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These voluntary recommendations are based on expert panel guidance received in 2019 and subsequent review and comment provided by the following expert group:

**Imad Absah, MD**

Mayo Clinic

**Janis Arnold, MSW, LICSW**

Boston Children's Hospital

**Shayna Coburn, PhD**

Celiac Disease Program at Children's National Hospital

**Amy Damast, PhD**

Temple Sinai Early Childhood Education Program

**Julia DeAngelo**

Children's National Hospital Health Advocacy Institute

**Meghan Donnelly**

Dr. Schär Institute

**Robyn Douglas, MPP, RDN**

Academy of Nutrition and Dietetics

**Tracy Ediger, MD, PhD**

Nationwide Children's Hospital

**Paula Fields, MSN, BSN, RN**

National School-Based Health Alliance

**Marilyn G. Geller**

Celiac Disease Foundation

**Monique Germone, PhD**

Children's Hospital Colorado

**Dena Goldberg**

Parent of Child with Celiac Disease

**Kayla Jackson, MPA**

School Superintendents Association (AASA)

**Hilary Jericho, MD**

University of Chicago Celiac Disease Center

**Mike Kalogiannis, MBA, PhD**

Dr. Schär Institute

**Benny Kerzner, MD**

Celiac Disease Program at Children's National Hospital

**Harriet Kuhn, PhD**

Montgomery County Public Schools

**Claire Lanham**

Gaithersburg Middle School

**Anne Lee, EdD, RDN**

Celiac Disease Center at Columbia University

**Dale Lee, MD**

Seattle Children's Hospital

**Maureen Leonard, MD, MMSc**

Mass General Hospital for Children

**Chloe Lerner**

Student with Celiac Disease

**Ian Leibowitz, MD**

Children's National Hospital/NASPGHAN

**Danny Mallon, MD**

Cincinnati Children's Hospital

**Alex Mays, MHS**

Healthy Schools Campaign

**Julia McBeth**

Celiac Disease Foundation



**Melinda McCartin, RN**

National Association of School Nurses

**Joyana McMahan**

Celiac Disease Program at Children's National Hospital

**Melissa Moore**

National CACFP Sponsors Association

**Blair Raber**

Celiac Disease Program at Children's National Hospital

**Catherine Raber**

Celiac Disease Program at Children's National Hospital

**Norelle Reilly, MD**

Celiac Disease Center at Columbia University

**Kristen Rowe, MS, RD, LD**

District of Columbia Public Schools

**Mary Shull, MD**

Children's Hospital Colorado

**Lori Shulman**

School District of the Chathams

**Jocelyn Silvester, MD, PhD**

Boston Children's Hospital/Society for the Study of Celiac Disease

**Amy Smith**

Parent of Child with Celiac Disease

**Lori Stern, CPNP-AC**

Children's National Hospital

**Alison Teres**

Parent of Child with Celiac Disease

**Alexia Thex**

National CACFP Sponsors Association

**Mary Vargas, JD**

Stein & Vargas, LLP

**Ritu Verma, MD**

University of Chicago Celiac Disease Center

**Vanessa Weisbrod**

Celiac Disease Program at Children's National Hospital

**Sandra Werness**

Global Autoimmune Institute

**Sweta Zaks**

Montgomery County Public Schools

**RESOLVE Facilitation Team**

**Mason Hines**

RESOLVE

**Sherry Kaiman**

RESOLVE

# INTRODUCTION

## Overview and Purpose

The *Voluntary Recommendations for Managing Celiac Disease in Learning Environments* guide is intended to support the implementation of a **Celiac Disease Management Plan (CDMP)** for the creation and maintenance of an environment that reduces the risk of gluten exposure for children with celiac disease. It is important to note that these recommendations do not advocate for making any changes to organizational structure nor for incorporating burdensome practices. Additionally, it is expected that learning environments can successfully develop and implement a CDMP without incurring significant costs.

While the implementation of recommendations in this guide is voluntary, all actions taken to manage children with celiac disease must be implemented in a way that is consistent with local, state, and federal laws. How

these laws apply will depend upon each individual child and situation. These recommendations do not address local, state, or district policies, so it is important that each institution verify the requirements in their individual jurisdiction.

The recommendations in this guide are based upon what is medically necessary for a child with celiac disease to succeed in a learning environment. Staff should work as a team with the child's medical provider and family to develop an individual 504 Plan comprised of accommodations that will help the child succeed. These recommendations may also be helpful for other children with a medical diagnosis from a physician that requires a gluten-free diet.

The CDMP refers consistently to "learning environments" which was defined by the expert group as:

**Learning environments** – learning for children occurs in both formal and informal settings. The term "learning environments" is therefore used broadly to include all settings where children learn, including but not limited to classrooms, sports fields, theaters, playgrounds, lunchrooms, libraries, field trips, outdoor education sites, laboratories, and any school-sponsored events.

A learning environment could also include a daycare center, in-home daycare or other child care facility where children engage in learning and social activities.

The purpose of these recommendations is to help learning environments understand the needs of children with celiac disease, build an inclusive and safe learning environment, and plan appropriately for gluten exposures. In a supportive environment, students with celiac disease can manage their condition successfully while fully participating in all learning and social activities.





## Methods

To develop these recommendations, the staff of the Celiac Disease Program at Children’s National Hospital (CNH), in partnership with the Celiac Disease Foundation and RESOLVE, developed a process to compile and review existing literature, solicit expert input, and conduct a study measuring the level of potential gluten exposure in a school setting.

To begin this process, the Celiac Disease Program at CNH and the Celiac Disease Foundation compiled and synthesized existing guidelines, recommendations, and other resources related to accommodating children with celiac disease in school settings from 12 hospital centers and advocacy groups. The resultant document served as a starting place for discussion with the expert group.

The recommendations were formed primarily by input, suggestions, and feedback from the expert group.

The 46-person expert group included a cross-section of health and education professionals and other stakeholders, specifically:

- Pediatric celiac disease programs affiliated with a children’s hospital facility (Children’s National Hospital, Boston Children’s Hospital, Children’s Hospital Colorado, Columbia University Medical Center, Comer Children’s Hospital, Seattle Children’s Hospital, Nationwide Children’s Hospital, Cincinnati Children’s Hospital Medical Center, Mayo Clinic, and Mass General Hospital for Children).
- Organizations representing schools (American Association of School Administrators, National Association of School Nurses, National School-Based Health Alliance, National CACFP Sponsors Association, Children’s Health Advocacy Institute, National Association of School Psychologists).
- Organizations with expertise in celiac disease and patient and physician advocacy (Celiac Disease Foundation and the Society for the Study of Celiac Disease).
- Four school districts (DC Public Schools, Montgomery County Public Schools, Fairfax County Schools, School District of the Chathams)
- One private preschool (Temple Sinai Early Childhood Education Program)
- One lawyer with expertise in 504 Plans
- One food manufacturer with expertise in gluten-free products
- Five parents of children with celiac disease
- One teenager with celiac disease

Each expert was asked to provide electronic feedback on the initial document prior to the first group in-person meeting. Their electronic feedback was incorporated by the Celiac Disease Program at CNH and the Celiac Disease Foundation into a revised set of recommendations.

At the first in-person meeting on March 11, 2019, the expert group reviewed and discussed the revised set of recommendations and provided additional feedback on their structure and content. Based on this feedback, the recommendations were revised again and distributed back to the expert group for further vetting via electronic survey. A fourth iteration of the recommendations was presented and refined at the second in-person meeting on July 22, 2019. At this meeting, consensus was reached on the recommendations. To reach consensus, participants voted on each recommendation and agreed to adopt all recommendations that achieved greater than 85% approval among the group.

To ensure that the recommendations for managing children with celiac disease are consistent with those for other chronic health conditions, and to reinforce the actions learning environments are already taking to protect the health of children, the expert group reviewed and drew from the disease management guidelines for other chronic diseases. Much of this document is based on the format and recommendations found in the following guides:

- *Voluntary Guidelines for Managing Food Allergies in School and Early Care and Education Programs. Centers for Disease Control and Prevention*
- *Students with Chronic Illness: Guidance for Families, Schools, and Students*
- *Managing Asthma: A Guide for Schools*
- *Helping the Student with Diabetes Succeed: A Guide for School Personnel*

Experts provided input on the structure, content, and language for the recommendations. As general guiding principles, they recommended that the recommendations should:

- Meet all requirements for use in a 504 Plan.
- Be applicable in a wide range of learning environments, including home-based child care centers, schools, and facilities that do and do not receive federal funding.
- Align with the format and level of detail in other guidelines for managing chronic conditions (e.g., food allergy, diabetes, and asthma).
- Adopt common terms and relevant practices (e.g., related to sanitation) from existing resources.
- Ensure the participation of management and administration to support the needs of children with celiac disease.
- Promote a strong partnership between learning institutions, families, medical providers, and students.

The resulting *Voluntary Recommendations for Managing Celiac Disease in Learning Environments* focuses on following four priority areas:

- Professional Development on Celiac Disease for Personnel Working with Children with Celiac Disease in Learning Environments
- Educating Children and Family Members About Celiac Disease
- Ensuring the Daily Management of Celiac Disease for Individual Children by Creating an Inclusive and Safe Learning Environment
- Developing a Plan for Gluten Exposures

Following the finalization of the recommendations, this guide, including the accompanying references to training materials and practical action lists, was created for the professionals that often make up a child's celiac disease care team.

# ABOUT CELIAC DISEASE AND THE GLUTEN-FREE DIET

## CELIAC DISEASE OVERVIEW

Celiac disease is a chronic autoimmune condition that affects approximately 1 percent of the global population. When patients with celiac disease eat gluten (a protein found in wheat, rye, and barley), this stimulates the immune system leading to inflammation and damage to the nutrient-absorbing villi in the small intestine. Both inflammation and malnutrition caused by celiac disease can lead to severe limitations of bodily function and complications that have significant effects on children and their families, as well as on the learning institution they attend.

Celiac disease was first recognized in young children, ages 6 to 18 months, who classically had symptoms of bloating, abdominal pain and diarrhea and signs of malnutrition. Until recently, this "classic" presentation was the only one described in medical textbooks. However, improved diagnostic tests have uncovered a much more extensive list of signs and symptoms of celiac disease and it is now recognized that celiac disease can develop in childhood or adulthood. Today, there are hundreds of recognized symptoms of this autoimmune disease that can affect any system of the body.

Today, the only treatment for celiac disease is a strict, gluten-free diet. All foods with wheat, rye, and barley must

be eliminated from the diet. The immune system can react to barely visible amounts of gluten so it is equally important that foods not be contaminated by coming into contact with any foods that contain wheat, rye, or barley during their preparation or service. Gluten is also found in everyday school supplies including modelling clay (Play-Doh®), finger paints, paper mâché and sensory table objects. A small number of medications and supplements contain gluten as do some lotions and sunscreens.

Although someone with celiac disease will not experience anaphylactic shock if they ingest gluten, they may experience symptoms, such as diarrhea, severe abdominal pain, behavioral changes, lethargy, skin rashes, or headaches, among many others. It is also important to recognize that some children may not have any immediate obvious symptoms after ingestion. Inadvertent or accidental ingestion of gluten affects a student's ability to learn, and seriously endangers the student's health, both immediately and in the long term.

The good news? Patients who strictly follow the gluten-free diet can begin to experience relief of symptoms in as little as one week, although it typically takes much longer for the small intestine to heal.

## GLUTEN-FREE DIET 101

Gluten is a protein found in **wheat, rye, and barley**. To keep a child safe from gluten exposure, it is really important for individuals managing a child with celiac disease to understand what gluten is. Gluten is most often found in food, but can also be found in medication,

vitamins, makeup, and school supplies. Individuals on a gluten-free diet must avoid all forms of wheat, rye, and barley, including any derivatives of these grains. A chart with the most common gluten-containing ingredients is on the following page.

## GLUTEN-CONTAINING INGREDIENTS

## GLUTEN-FREE INGREDIENTS

Having a strong understanding of gluten-free ingredients will help with the daily management of a child with celiac disease. In their natural form, fresh fruits and vegetables, eggs, meats, seafood, tofu, legumes and unflavored dairy

products are naturally gluten-free. A brief list of common ingredients is below, but please refer to the **Gluten-Free Ingredient Glossary** for a full description of each ingredient.

Acorn Flour	Almond Flour	Amaranth	Arborio Rice	Arrowroot
Basmati Rice	Bean Flours	Brown Rice Flour	Buckwheat	Calrose Rice
Canola	Cassava	Channa	Chickpea Flour	Coconut Flour
Corn Flour	Corn Meal	Cornstarch	Cottonseed	Dal
Dasheen Flour	Enriched Rice	Fava Bean Flour	Flax	Flax Seed
Flaxseed Meal	Garbanzo	Glutinous Rice	Guar Gum	Hominy
Kasha	Lentils	Millet	Peanut Flour	Potato Flour
Potato Starch	Quinoa	Red Rice	Rice Bran	Rice Flour
Sesame	Sorghum	Soy	Soybeans	Sunflower Seeds
Sweet Rice Flour	Tapioca	Tapioca Flour	Taro Flour	Teff
White Rice Flour	Xanthan Gum	Yeast	Yuca	

## PREVENTING GLUTEN CROSS-CONTACT

Adhering to a strict gluten-free diet means avoiding any chance of cross-contact with gluten-containing products, but that *does not require a sterile, 100% gluten-free environment*. By taking a few precautions, it is possible to store, prepare, and serve both gluten-free and gluten-containing foods in the same environment and still keep a child safe from gluten exposure.

**If you can prevent bacteria from contaminating a kitchen or eating space, you can also prevent gluten contamination from cross-contact.** If you prepare gluten-containing foods or if children eat gluten-containing foods in a certain

space, then you must clean with the same rigor that you would if you had just prepared raw chicken in the same space. For example, wash pots, pans, utensils, workspaces, and countertops with hot soapy water before bringing out gluten-free foods. In a classroom, wipe down tables with approved cleaning solutions prior to a child with celiac disease eating on that surface.

For detailed instructions on preventing cross-contact in cafeterias and shared kitchens, please refer to the training video on **Safe Gluten-Free Practices in Shared Kitchen Environments**.

## FINDING GLUTEN-FREE FOODS

There are no federal laws requiring that a product be labeled as gluten-free. However, in 2013, the U.S. Food and Drug Administration (FDA) announced the **Gluten-Free Food Labeling Rule**. According to the rule, if a manufacturer chooses to label a product as gluten-free, then they are claiming that it contains less than 20 parts per million (ppm) gluten. It's very important to note that using a gluten-free label is voluntary, so a manufacturer does not have to label a product as gluten-free, even if it is. In addition, the rule does not set out requirements for testing for gluten.

Furthermore, there is no nationally-accepted or required certification for gluten-free. There are a number of third-party companies that charge manufacturers a fee to test their products for gluten. If a product meets the certification standard, the manufacturer is able to use the certifier's chosen gluten-free symbol. If a product meets the FDA standard, the manufacturer can choose to use any form of the words "gluten-free" on its label. Here are some of the commonly seen gluten-free symbols as of February 2020:



## READING FOOD LABELS

It is very important that individuals managing a child with celiac disease read food labels carefully, especially if a product does not clearly bear a gluten-free claim. Make sure to refer to the list of unsafe and safe ingredients.

The Food Allergen Labeling and Consumer Protection Act (FALCPA), which went into effect in January 2006, requires consumer-friendly labeling on packages of the eight most common food allergen items: wheat, milk, soy, eggs, peanuts, tree nuts, fish and shellfish. You'll most often see these ingredients show up in an "Allergen Statement" that appears right below the ingredients list.

FALCPA makes it easy for people with celiac disease to identify wheat in a product, but **unfortunately, barley and rye are not included in the Act's rules, so ingredient labels must always be read.**



# The Impact of Celiac Disease on Learning



## PHYSICAL SYMPTOMS DISRUPT LEARNING

When exposed to gluten, students with celiac disease may experience a variety of physical and emotional symptoms that may negatively impact their ability to learn and thrive academically and socially. Symptoms can be anxiety-provoking, embarrassing, painful, and distracting. As a result of these symptoms or fears of becoming ill, students may be unable or unwilling to attend school at times. Physical and emotional symptoms negatively impact a student's ability to focus, learn, and perform at their usual level, and may have additional negative consequences due to unexcused absences and missed work.

## EXCLUSION AND ISOLATION

The gluten-free diet can interfere with academic and social activities, which can result in a sense of exclusion and isolation. It is challenging to participate in class lessons involving food or materials containing gluten, eat meals with peers, partake in celebratory treats, and travel on class trips. This can interfere with academic and social-emotional development.

## BULLYING AND DISCRIMINATION

Students with celiac disease and their parents have reported bullying and discrimination because of both celiac disease and the gluten-free diet treatment. Eating different foods, asking questions, or having overt symptoms that are noticeable to others may attract negative attention. Alternatively, students who are apparently asymptomatic may be judged by individuals who doubt the validity of their diagnosis and may not take it seriously. In either case, students may experience teasing, taunting, harassment, or bullying by peers, teachers, coaches, and other adults. Consequently, many students and their parents find it difficult, if not impossible, to advocate for their needs.

## RISKS FOR GLUTEN EXPOSURE

Many students with celiac disease find it difficult to avoid gluten exposure at school, which is often a primary source of risk. Up to 44% of children and teens do not fully follow a strict gluten-free diet, and dietary transgressions often occur when they eat with their peers. Students are also at risk of exposure to gluten from class food celebrations and cross-contact with gluten-containing materials (e.g., Play-Doh®, paper mâché). Students with celiac disease who feel less integrated into school activities may be less likely to succeed on the gluten-free diet resulting in negative short- and long-term health consequences.

## Important Relevant Research

Research from Children's National Hospital in Washington D.C. and Boston Children's Hospital provides important data regarding the risk of gluten exposure in schools. The paper, "A Quantitative Assessment of Gluten Cross-contact in the School Environment for Children with Celiac Disease" published in the Journal of Pediatric Gastroenterology and Nutrition helps to answer common questions about how to keep children who require gluten-free diets (GFD) safe at school.

The study team tested four scenarios where it was thought that gluten transfer could be high enough to lead to cross-contact resulting in a gluten-free food having a gluten concentration greater than 20 ppm. This threshold was chosen because food containing less than 20 ppm (less than 0.002 percent gluten) is considered to be "gluten-free" by the U.S. Food and Drug Administration, and products containing less than 20 ppm gluten can be labelled "gluten-free" in the United States, Canada, and the European Union. The scenarios tested were:

- **Playing with Play-Doh® modelling clay:** a 3-ounce container of Play-Doh® contains over 32,000 ppm gluten, which is nearly as much as in a slice of wheat bread. Even when children did not wash their hands, there were no cases of gluten transfer from hands to a slice of gluten-free bread resulting in a gluten concentration >20 ppm. In two cases, bread wiped on the table surface with visible contamination (i.e. pea-sized or larger pieces of Play-Doh®) had gluten levels >20 ppm.
- **Sensory tables with dry and wet pasta:** After children played with wet pasta in sensory tables, 9/10 children had visible contamination on their hands that transferred to gluten-free bread resulting in a gluten concentration >20 ppm. The child who did not have any transfer had minimal contact with the wet pasta because they did not like how it felt on their hands. Playing with dry pasta did not produce detectable gluten-transfer.
- **Paper Mâché:** All 10 children who used paper mâché had a significant amount of visible residue on their hands and transferred high amounts of gluten to gluten-free bread.
- **Baking project:** Thirty children rolled gluten-containing dough and cut out cookies on a surface

dusted with gluten-containing flour. After washing hands with water, soap and water or wet wipes, gluten transfer from hands to a slice of gluten-free bread was detectable for 11/30 participants. Gluten transfer from the surface occurred more than 70% of the time, even after surfaces were washed.

Traditionally, medical providers have made recommendations about avoiding cross-contact based on assumptions and expert opinion, but with very little actual data. This is the first study to examine gluten exposure during common educational activities and it provides useful data to help guide assessment of risk of cross-contact and to advise for the management of celiac disease in learning environments.

Suggestions based on study findings:

### Modelling Clay:

- Children with celiac disease (and others who follow a GFD) should use gluten-free modelling clays.
- Play-Doh® brand modelling clay is wheat-based and contains significant amounts of gluten. It should not be eaten or played with by children who may eat the Play-Doh®, put their hands in their mouth, or engage in other behaviors that put them at risk of ingestion.
- In situations when gluten-free modelling clay is not available and children are not at risk of ingestion, its use in a supervised setting with scrupulous cleaning of hands and surfaces to remove all visible contamination is likely safe.

### Pasta:

- Children with celiac disease (and others who follow a GFD) should use gluten-free pasta for art and other classroom projects.
- Gluten-containing dry pasta appears to pose a low risk unless there is oral exposure.
- Gluten-containing wet pasta (e.g., sensory tables) tends to adhere to hands and other surfaces and poses a much higher risk of environmental contamination and gluten exposure than dry pasta.

### Gluten-Containing Flour, Powders, and Pastes:

- Children with celiac disease (and others who follow a GFD) should only work with gluten-free flours, powders, and pastes (such as paper mâché).

- In classroom environments, there is a risk if gluten-containing flours are used. This risk is related to aerosolization of flour, spread of flour dust, residual flour when surfaces are not cleaned adequately, and unanticipated contact (e.g., spills, food fights).
- In a cooking classroom environment where **flour** is used, the best option is for a child with celiac disease to use gluten-free ingredients, clean utensils and equipment, and a clean workspace. The gluten-free area should be at least 6-feet from gluten-containing materials.
- Use of gluten-containing liquids (e.g., pancake mix) or wet pastes is a risk for gluten contamination because it can be difficult to remove all traces of gluten from hands and work surfaces.

It is important to recognize that handwashing and environmental decontamination practices are highly variable, particularly among children and in busy classroom environments. While thorough cleaning procedures effectively remove gluten from most

surfaces, it may be challenging to ensure that these occur consistently. It is also important to consider the developmental stage of the individual child and how this might affect their exposure risk. For example, some children suck their thumb or put their hands or other objects (including Play-Doh®) in their mouth.

- Surfaces should be cleaned adequately before a child with celiac disease works in an environment where wheat flour or wet gluten-containing materials have been used.
- Adequate supervision when gluten-containing materials are being used in the classroom setting is essential.
- Hand washing is important.
- Food should never be eaten if there is visible contamination on hands, surfaces, or the food itself.

All learning environment staff must consider these factors as they develop plans for managing the risk of gluten exposure for children with celiac disease.



## TRAINING RESOURCES FOR CELIAC DISEASE AND THE GLUTEN-FREE DIET

Training resources for managing children with celiac disease are available free of charge. Below are references to training seminars designed to directly complement these recommendations. These courses can be accessed at <https://www.openpediatrics.org/>

### CELIAC DISEASE OVERVIEW

In this celiac disease primer video, physicians from pediatric celiac disease programs will explain the basic science behind this chronic autoimmune disease and its effects on children.

### THE GLUTEN-FREE DIET

The gluten-free diet – the only current treatment for celiac disease – will be discussed in detail. The training will also address selecting gluten-free food products, reading food labels, and preventing gluten cross-contact.

### FEDERAL LAWS AND REGULATIONS THAT APPLY TO CELIAC DISEASE IN LEARNING ENVIRONMENTS

Several federal laws apply to children with celiac disease in learning environments. This video describes these laws and how they apply to developing a celiac disease management plan.

### SUPPORTING EDUCATIONAL AND SOCIAL DEVELOPMENT OF CHILDREN WITH CELIAC DISEASE

This presentation addresses the impact of celiac disease on learning and social-emotional development including bullying, exclusion, and isolation. Through a combination of case-based discussions, participants will gain a thorough understanding of how children with celiac disease can be fully integrated into the learning environment.

### FAMILIES WITH CELIAC DISEASE: WHAT TO EXPECT AT SCHOOL

Whether your child was recently diagnosed with celiac disease or you've experienced conflict with the gluten-free diet in a learning environment, this training seminar and video provides a step-by-step guide for parents or guardians of children with celiac disease to plan for a safe year in a learning environment. The course will cover

reasonable expectations for setting up accommodations and processes for building a plan that allows every child to fully participate in all learning activities.

### FOR SCHOOLS: THERE'S A STUDENT WITH CELIAC DISEASE AT MY SCHOOL. NOW WHAT?

Often learning environment professionals must simultaneously manage and provide accommodations for learners with a variety of different conditions, including celiac disease and the minimization of gluten exposure. This brief training video outlines key strategies to methodically provide for a safe learning environment for children with celiac disease.

### FOR MEDICAL PROVIDERS WHO DIAGNOSE AND MANAGE CELIAC DISEASE PATIENTS

You've just diagnosed a patient with celiac disease. This video outlines how a medical provider can prepare a family with celiac disease for navigating a learning environment and setting up appropriate accommodations to keep the child healthy.

### WHERE GLUTEN IS FOUND IN SCHOOL AND HOW TO PREVENT EXPOSURE

Gluten is a protein in wheat, rye, and barley. While it's most commonly found in food, gluten is also used in many other items, including school supplies such as Play-Doh®, modelling clay, paper mâché, art supplies, glue, and ingredients used in home economics classrooms. This video highlights common places for gluten cross-contact in learning environments and presents strategies to mitigate the risk of gluten exposure for children with celiac disease.

### SAFE GLUTEN-FREE PRACTICES IN SHARED KITCHEN ENVIRONMENTS (CAFETERIAS)

If the transfer of bacteria from raw chicken to other foods can be prevented, then transfer of gluten to gluten-free foods can also be avoided. This training video highlights areas of concern for gluten cross-contact in shared kitchens and offers strategies for food purchasing, storage, and handling to prepare gluten-free meals for children with celiac disease in a kitchen environment where gluten-containing foods are also prepared.



## Federal Laws and Regulations that Govern Celiac Disease in Learning Environments

### **SECTION 504 OF THE REHABILITATION ACT OF 1973**

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination in all institutions receiving federal financial assistance including schools, on the basis of disability, including certain diseases like celiac disease. This requires any educational institution receiving federal funding to provide educational programming that is “designed to meet the student’s individual educational needs as adequately as the needs of non-disabled students are met.”<sup>1</sup> In short, the law requires modifications for any student covered under Section 504 that appropriately meets the needs of the student without drastically altering the structure of the educational institution.

### **AMERICANS WITH DISABILITIES ACT OF 1990**

The Americans with Disabilities Act of 1990 (ADA) defines a disability as “a physical or mental impairment that substantially limits one or more major life activities” (42 U.S.C. § 12102). Eating and major bodily functions (among them the digestive and immune systems) are included in the definition. Exposure to gluten for a child with celiac disease can affect a student’s ability to learn as well as seriously endanger the individual’s health. Because of these circumstances, individuals with celiac disease qualify for protection under this law.

## U.S. FOOD AND DRUG ADMINISTRATION (FDA) GLUTEN-FREE FOOD LABELING LAW

The FDA began to regulate the usage of the term "gluten-free" on food labels in 2014. While a gluten-free statement on a label remains a voluntary disclosure, it allows for consumers to have a consistent understanding about the level of gluten in their food. The law states that in order to be consistent with FDA guidelines, a product that is labeled "gluten-free" must:

- Exclude any ingredient that is composed of wheat, barley, rye, or any crossbreeds or derivatives of these products
- OR
- Contain less than 20 parts per million (ppm) of gluten

As such, the minimum requirement for a safe food item or material for a child with celiac disease must meet these criteria.

## NATIONAL SCHOOL LUNCH ACT

The National School Lunch Act of 1946<sup>2</sup> was created to provide qualified students free or reduced cost school lunch meals. The U.S. Government achieves this through subsidies to both public and private schools. A gluten-free diet can be almost twice as expensive as a conventional diet, putting many families through financial stress.<sup>3</sup> A gluten-free option for students is included in a qualified student's right to have a free or reduced lunch.

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<sup>1</sup> (Citation: U.S. Department of Education, <https://www2.ed.gov/about/offices/list/ocr/504faq.html> \ \ <https://www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>)

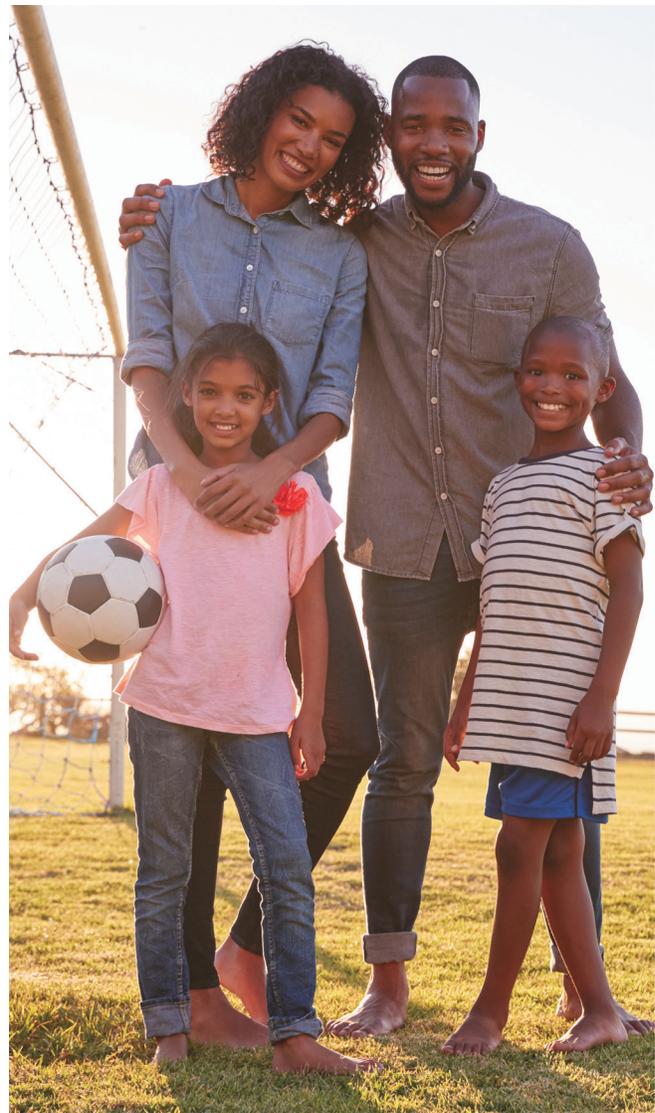
<sup>2</sup> (2) 79 P.L. 396, 60 Stat. 230

<sup>3</sup> Lee, A.R.; Wolf, R.L.; Lebuohl, B.; Ciaccio, E.J.; Green, P.H.R. Persistent Economic Burden of the Gluten Free Diet. *Nutrients*. 2019, 11, 399.

<sup>4</sup> P.L. 89-642

## CHILD NUTRITION ACT

The Child Nutrition Act of 1966<sup>4</sup> helped strengthen and expand the National School Lunch Act of 1946. Among the expansions were the Special Milk Program, a free or reduced-cost breakfast at school, and financial assistance to schools for equipment that would help extend breakfast and lunch services to more children. Most importantly, it paved the way for the U.S. Department of Agriculture (USDA) to set uniform standards for nutrition in school breakfasts and lunches. This law would apply to any student qualified for a free or reduced lunch who also requires a gluten-free diet, ensuring that appropriate and nutritious meals are served.



# THE CELIAC DISEASE MANAGEMENT PLAN (CDMP)

## The Celiac Disease Management Plan contains four key sections:

- Section 1: Formal Professional Development on Celiac Disease for Personnel Working with Children with Celiac Disease in Learning Environments
- Section 2: Educating Children and Family Members About Celiac Disease
- Section 3: Ensuring the Daily Management of Celiac Disease for Individual Children by Creating an Inclusive and Safe Learning Environment
- Section 4: Developing a Plan for Gluten Exposures

### PURPOSE OF RECOMMENDATIONS:

These recommendations are intended for use to develop an individual 504 Plan for a child with celiac disease. The recommendations may also be helpful for other children with a medical diagnosis from a physician that requires a gluten-free diet.

### DEFINITION OF A LEARNING ENVIRONMENT:

Learning environments – learning for children occurs in both formal and informal settings. The term “learning environments” is therefore used broadly to encompass all settings where children learn including but not limited to classrooms, child care centers, sports fields, theaters, playgrounds, lunchrooms, libraries, field trips, outdoor education sites, laboratories, and any school-sponsored events.

# Formal Professional Development on Celiac Disease for Personnel Working with Children with Celiac Disease in Learning Environments

**1(a) Provide GENERAL training and resources on celiac disease and the gluten-free diet for all staff and other personnel with formal arrangements to work in learning environments.**

All personnel who interact with children with celiac disease should receive general training about celiac disease and the gluten-free diet. These personnel may include but are not limited to: administrators; classroom, substitute, and specialty teachers; athletic coaches; school counselors, psychologists, and therapists; librarians; building services staff; tutors; child care providers and education program staff; volunteers and other community partners who will interact with children with celiac disease. General training should include the following content:

- An overview of celiac disease and the gluten-free diet
- Definitions of key terminology, including celiac disease, gluten, and gluten-free
- The variability of signs and symptoms of gluten exposure
- General strategies for reducing and preventing exposure to gluten (in food and non-food items)
- Institutional policies on bullying and harassment and how they apply to children with celiac disease
- Understanding of the policies and practices regarding celiac disease and the gluten-free diet

**1(b) Provide IN-DEPTH training and resources for health care professionals and personnel who have frequent interaction with children with celiac disease.**

All personnel who are directly responsible for a child with celiac disease at any point during the day should receive in-depth training about celiac disease and the gluten-free diet. These personnel may include but are not limited to: school nurses and other health care professionals; classroom and specialty teachers; nutrition and food service staff; athletic coaches; and child care and education program staff. In-depth training should include **all of the general training content** plus the following:

- Information about federal laws that apply to accommodating children with celiac disease, specifically Section 504 of the Rehabilitation Act and the Americans with Disabilities Act
- Information about gluten-containing materials and common pathways of exposure to gluten in learning environments
- Information about the ranges of possible short- and long-term effects of gluten exposure on children's behavior and ability to learn
- Strategies for building an inclusive environment for children with celiac disease while minimizing the potential for gluten exposure, which may include:
  - Information on reading labels and identifying gluten in products
  - Instructions on proper hand, surface, appliance, and utensil sanitizing methods to remove gluten
  - The importance of providing emotional support to children with celiac disease
- Safe procedures for storing and/or accessing gluten-free foods
- The importance of not allowing children to share food items without permission
- How to respond to a gluten exposure, including notifying parents/guardians
- How to help children handle symptoms resulting from gluten exposure



## Educating Children, Parents/Guardians and Families About Celiac Disease

### 2(a) Teach Children about Celiac Disease.

Information about celiac disease should be incorporated into health education modules in a manner similar to information about health conditions such as food allergies, asthma, and diabetes. Children, particularly those who share a learning environment with a child with celiac disease, should learn about the condition in a way that is consistent with their age and developmental level according to the National Health Education Standards<sup>5</sup>. Education should focus on raising awareness and understanding of celiac disease and on supporting and accepting those with health conditions. Education should not identify specific children with celiac disease. As appropriate to the age and developmental level of the students, education about celiac disease may include:

- Understanding that some children are unable to tolerate certain foods for health reasons
- Understanding why it is wrong to bully or tease others who are managing a special diet
- Understanding how and why to find a teacher or other supervising adult who can help respond when a child with celiac disease is feeling ill
- Understanding why it is important to only touch or eat one's own food during meals and snack times

### 2(b) Teach Parents/Guardians and Families about Celiac Disease.

The success of a Celiac Disease Management Plan relies on the support and participation of families of children with celiac disease, as well as that of families with children who do not have celiac disease. All parents/guardians should be provided with information about celiac disease and the policies and practices in place to protect children and build an environment that is inclusive of all children, regardless of their dietary needs or other health conditions. Information about celiac disease can be incorporated into information distributed about other health conditions such as food allergies, asthma, and diabetes. This information should not identify specific children with celiac disease. Information distributed to parents may include but is not limited to:

- How the institution can prevent gluten exposure for children with celiac disease
- How parents can help build an inclusive community for all children with celiac disease as well as other food intolerances, allergies, or chronic conditions
- Protocols and policies for preventing bullying and teasing of students with special dietary needs

<sup>5</sup> The National Health Education Standards (NHES) provide a framework for designing or selecting curricula to promote and support age-appropriate, health-enhancing behaviors for students in all grade levels.



## Ensuring the Daily Management of Celiac Disease for Individual Children by Creating an Inclusive and Safe Learning Environment

### 3(a) Create an inclusive environment that avoids exposure to gluten.

The only treatment for celiac disease is a lifelong gluten-free diet. Policies and practices that create a safe, inclusive environment for children with celiac disease by reducing the potential for exposure to gluten in the classroom, other learning spaces, common use areas, and eating spaces should be implemented.

**Table 1** offers recommended practices for accommodating children with celiac disease in learning environments. The recommendations are intended to ensure that children with celiac disease are safe, feel included, and are supported in their educational, social, and emotional development.

The accommodations provided an individual child should be documented in the child's specific 504 Plan. *Not every recommendation will apply to every child or every institutional setting.*

### EXAMPLE APPROACHES:

Some institutions have implemented a **no-food policy**. This policy prohibits food items from being used in classroom or learning activities, celebrations, festivals, or rewards. This method of limiting exposure to food protects children with celiac disease as well as those with food allergies and other dietary restrictions.

Some institutions provide, or allow parents to provide, a **gluten-free option** for the child with celiac disease in their classroom or learning activities, celebrations, festivals, and rewards. This method allows children with celiac disease to participate in all programs, but requires careful attention to ensure that the gluten-free option is offered free of cross-contact from gluten-containing ingredients.

Some schools are **gluten-free, peanut-free, and/or common allergen-free**. This method allows children with celiac disease to participate without being identified as having special dietary needs.

Table 1:

## RECOMMENDED PRACTICES FOR REDUCING RISK OF GLUTEN EXPOSURE FOR CHILDREN WITH CELIAC DISEASE

CLASSROOM OR OTHER LEARNING ENVIRONMENT	EATING SPACES	FIELD TRIPS, EVENTS, OTHER OFF-SITE ACTIVITIES
<ul style="list-style-type: none"> <li>● <b>Avoid the use of gluten</b> in class projects, arts, science experiments, and other learning activities.</li> <li>● <b>Provide a gluten-free option</b> for children with celiac disease for any learning-environment-sponsored event involving food (e.g., parties, holiday celebrations, snacks, or rewards).</li> <li>● Use <b>non-food incentives</b> for prizes, gifts, and awards</li> <li>● As appropriate to their age and ability, <b>help children with celiac disease read and understand the labels of foods provided by others</b>, so they can learn to avoid ingesting gluten.</li> <li>● If food is provided by families for an activity, then <b>provide 48 hours notification to the parents/guardians</b> of children with celiac disease to determine an appropriate accommodation. The notification may include a description of the food item(s) and an ingredients list when available.</li> <li>● If <b>meals and/or snacks are stored</b>, designate space for gluten-free food storage that is separate from gluten-containing food storage.</li> <li>● Require children with celiac disease to <b>wash their hands</b> with water and soap before and after eating.</li> <li>● Require children with celiac disease to <b>wash their hands</b> with water and soap after handling materials that contain gluten.</li> <li>● Encourage <b>parents of children with celiac disease to provide gluten-free snack or treat items</b> to be stored in the learning environment or other agreed upon storage space in the event of an unexpected activity involving food.</li> <li>● If there is a child with celiac disease in the learning environment, then include information about celiac management procedures in instructions provided to <b>substitute teachers</b>.</li> </ul>	<ul style="list-style-type: none"> <li>● The food service provider should <b>offer reasonably equivalent gluten-free food options</b> for children with celiac disease that are cooked using methods to prevent cross-contact with gluten.</li> <li>● All gluten-free food options served to children with celiac disease must meet the <b>FDA's definition of gluten-free for food labeling</b>.</li> <li>● <b>Review labels</b> of food items served to children with celiac disease for gluten-containing ingredients at the time of each new purchase.</li> <li>● If food is provided by families for an activity, then <b>provide 48 hours notification to the parents/guardians</b> of children with celiac disease to determine an appropriate accommodation. The notification may include a description of the food item(s) and an ingredients list when available.</li> <li>● If food is prepared in the learning environment, <b>designate a gluten-free safe food preparation area</b> with either dedicated or appropriately-sanitized kitchen tools. If a dedicated area is unavailable, then <b>clean preparation areas thoroughly</b> before preparing gluten-free foods. (See (3b))</li> <li>● Provide copies of meal menus, including <b>gluten-free food options</b>, to parents/guardians of children with celiac disease at least one week prior to serving to assist families in meal planning.</li> <li>● <b>Clean the eating surface where the child with celiac disease might eat</b> so that the child can, like other children, choose where to sit during eating times.</li> <li>● Encourage children and staff to <b>wash their hands</b> with soap and water before and after handling or eating food.</li> <li>● <b>Share recipes, food labels, and ingredient lists</b> of foods used to prepare gluten-free meals and/or snacks with parents/guardians of children with celiac disease, as requested.</li> </ul>	<ul style="list-style-type: none"> <li>● <b>Avoid off-site activities that would exclude children with celiac disease</b> from safe participation (e.g., at a bakery or other venue that will not allow gluten-free accommodations).</li> <li>● <b>Engage the parents/guardians</b> of children with celiac disease in planning for accommodations for off-site activities.</li> <li>● If <b>food will be provided by an outside vendor</b>, then notify the vendor of the gluten-free needs of children with celiac disease and request a written plan detailing the food that will be provided, accompanying labels or ingredient lists, and the method of preparation.</li> <li>● If the learning environment will provide the food for an off-site activity, then ensure that meals and snacks are <b>packaged in a way that prevents cross-contact</b> and are <b>clearly labeled as gluten-free foods</b>.</li> <li>● If the parents/guardians provide food for the activity, then <b>ensure there is a method for safely transporting and serving</b> the food to the child with celiac disease in a way that prevents cross-contact with other food items.</li> </ul>

CLASSROOM OR OTHER LEARNING ENVIRONMENT	EATING SPACES	FIELD TRIPS, EVENTS, OTHER OFF-SITE ACTIVITIES
<ul style="list-style-type: none"> <li>● If food is ordered from a restaurant or outside vendor (e.g., Pizza Friday), then <b>consult with the parents/guardians of children with celiac disease to develop an accommodation plan. This may include ordering from a restaurant or vendor with specific knowledge</b> about celiac disease and gluten-free food handling, or another solution if no such restaurant or vendor is available or acceptable (e.g., bring in a gluten-free pizza from home).</li> <li>● <b>Notify the parents/guardians</b> of the child with celiac disease of any learning activities that may require an accommodation <b>at least 1 week</b> prior to the activity.</li> <li>● The <b>method for parent/guardian notification</b> (e.g., phone, email, written letter) of accommodations should follow the institution's standard parent/guardian notification procedures.</li> <li>● If the learning space is utilized for other functions (e.g., PTAs, community groups), then <b>notify these users of all policies and rules regarding use of food or food-based materials.</b></li> <li>● If gluten-containing foods or materials are used during other functions, then <b>ensure the space is properly cleaned</b> prior to use by children with celiac disease. (See 3(b))</li> <li>● <b>Report all suspected gluten exposures</b> (e.g., cross-contact, ingredient list errors, menu changes, etc.), to designated staff member and parents/guardians immediately upon awareness.</li> <li>● In the case of a suspected gluten exposure, regardless of whether the exposure happened at home or at the learning environment, <b>provide the child with celiac disease unrestricted access to the bathroom facility and health/counseling staff.</b></li> </ul>	<ul style="list-style-type: none"> <li>● <b>Maintain copies of all food labels</b> for at least 48 hours after serving a gluten-free food product in case a child with celiac disease has a reaction.</li> <li>● <b>The food service provider should maintain an up-to-date contact list of vendors and manufacturers</b> for inquiries about ingredients.</li> <li>● <b>Develop a standard procedure for identifying children</b> with celiac disease who need to be served a gluten-free meal that is consistent with the Family Educational Rights and Privacy Act of 1974 (FERPA).</li> <li>● <b>Report all suspected gluten exposures</b> (e.g., cross-contact, ingredient list errors, menu changes), to designated staff member and parents/guardians immediately upon awareness.</li> <li>● If food is prepared on site at the learning environment, then <b>designate a staff member to oversee upkeep of gluten-free food preparation, food ordering, and the serving</b> to children with celiac disease. Identify a back-up individual or team in case of absence from the primary designee.</li> <li>● If the learning environment is required to maintain an <b>emergency supply of food</b> based on state and local laws, <b>keep gluten-free foods</b> for children with celiac disease.</li> <li>● In the case of a suspected gluten exposure, regardless of whether the exposure happened at home or at the learning environment, <b>provide the child with celiac disease unrestricted access to the bathroom facility and health/counseling staff.</b></li> </ul>	<ul style="list-style-type: none"> <li>● Ensure those responsible (<b>chaperones/staff</b>) for a child with celiac disease are <b>informed of the accommodation plans</b> for children with celiac disease.</li> <li>● <b>Inform the parents/guardians</b> of children with celiac disease of the plan for accommodating their children <b>at least 1 week</b> prior to the activity.</li> <li>● Consider inviting the parents/guardians of children with celiac disease to <b>accompany activities that require an accommodation.</b></li> <li>● <b>Report all suspected gluten exposures</b> (e.g., cross-contact, ingredient list errors, menu changes), to designated staff member and parents/guardians immediately upon awareness.</li> <li>● In the case of a suspected gluten exposure, regardless of whether the exposure happened at home or at the learning environment, <b>provide the child with celiac disease unrestricted access to the bathroom facility and health/counseling staff.</b></li> </ul>

### 3(b) Follow cleaning policies and procedures to prevent gluten from contacting gluten-free foods or materials.

Nutrition and food service staff are required to follow local food safety and sanitation laws and to be trained in practices that prevent food, surface-to-food, and food-to-food contamination. These laws and practices also serve to help prevent cross-contact with gluten. Suggested practices for cleaning and sanitation to prevent gluten from coming into contact with gluten-free foods or materials include<sup>6</sup>:

- Clean and sanitize (with soap and water or all-purpose cleaning agents that meet state and local food safety regulations) all surfaces that come into contact with food in kitchens, classrooms, and other locations where food is prepared or eaten.
- Clean and sanitize food preparation equipment, such as cutting boards, platters, food slicers, and utensils before and after use to prevent cross-contact with gluten.
- Clean and sanitize trays and baking sheets after each use.
- Prepare food separately for children with celiac disease. Strategies may include preparing gluten-free foods first, using a separate work space and

equipment, or labeling and storing gluten-free items before preparing other foods.

- Train all personnel who prepare, handle, or serve food on how to read labels to identify gluten in food. Make sure that personnel are knowledgeable about current food labeling laws regarding the identification of gluten (wheat, rye, barley, and contaminated oats). Food labels should be reviewed every time the food is purchased because food ingredients and labels change often.
- Use appropriate hand-washing procedures that emphasize the use of water. Hand sanitizers are not effective in removing gluten. Please refer to page 14 on important relevant research for data on removing gluten safely from the hands and work surfaces.

It is important to remember that meals and snacks may be served in locations other than kitchens or cafeterias and handled by staff members other than the food service staff. When developing policies and procedures for food handling, consider all possible situations where food might be prepared or served, any personnel who might be involved, what information/training those personnel need, and the state and local food safety regulations that apply to the context, if any, to help prevent cross-contact with gluten in these situations.

<sup>6</sup> These recommendations are adapted from the practices outlined in the *Voluntary Guidelines for Managing Food Allergies in School and Early Care and Education Programs, Section 5b*.

## Developing a Plan for Gluten Exposures

If a child with celiac disease is exposed to gluten, they will not experience immediate life-threatening symptoms, such as anaphylaxis. However, they may experience some of the following: diarrhea, vomiting, nausea, constipation, abdominal pain, skin rashes, headaches, joint pain, fatigue, behavioral changes/mood disturbances, or other symptoms. It is important to note in the individual child's 504 Plan any specific symptoms the child commonly experiences upon gluten exposure.

The gluten exposure may or may not have occurred in the learning environment. The onset and duration of symptoms may range from minutes to hours to days in children with celiac disease. As such, staff should assist a child experiencing symptoms. This includes:

- **Notification of parents/guardians of suspected gluten exposure by a designated staff member** immediately upon awareness

- Provision of **unrestricted access to the bathroom facility and health/counseling staff** for the child with celiac disease
- Seeking of **further medical attention and alerting of parents/guardians** if the student:
  - Vomits continuously
  - Appears to be severely dehydrated
  - Reports severe abdominal pain or distention
  - Reports symptoms that are not typical of that child's usual gluten reaction (if known)
- A designated staff member should review the gluten exposure and response to the exposure with the parent/guardian of the child with celiac disease and develop a strategy to prevent future exposures

# PUTTING RECOMMENDATIONS INTO PRACTICE

The following sections describe actions and responsibilities of key learning environment staff members, physicians/medical providers, parents/guardians, and children with celiac disease as defined by participants in the expert group. These action lists do not represent legal checklists for what individuals must do to comply with state and federal laws. Rather, they are steps for administrators, school nurses, learning environment personnel, physicians/other medical providers, parents/guardians, and children to take to ensure effective management of celiac disease.



## How to Use the Action Lists

- Print and distribute each action list to the appropriate individuals.
- Make copies of action lists to provide to substitute personnel so they are aware of their responsibilities for caring for a child with celiac disease.
- Review the action sheets annually with all individuals involved in the management of celiac disease to ensure that everyone understands their roles and responsibilities.

# School Boards and District Staff – Putting Recommendations into Practice

Please distribute to the superintendent, 504/IEP coordinator, or other school administrators responsible for coordinating student health services on a district-wide level.



- **Understand and ensure compliance with the federal and state laws** that apply to students with celiac disease. Understand the procedures for implementing laws including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Learn about celiac disease and the gluten-free diet.**
  - Attend a training seminar and review the provided documents. These seminars and materials are available free of charge at <https://www.openpediatrics.org>.
- **Provide leadership in developing school policy** related to celiac disease management at school.

This includes:

- Ensuring availability of a school nurse and trained celiac disease management personnel when the student is in school or at school-sponsored activities.
- Obtaining input from local or regional experts on developing appropriate policies regarding food in the classroom and school-sponsored events.
- **Allocate sufficient resources for helping students with celiac disease in the school setting.** (e.g., gluten-free food and classroom materials).
- **Include gluten-free provisions for students with celiac disease in emergency/disaster planning if required to by state law.** (e.g., lockdown or evacuation).
- **Monitor schools attended by students with celiac disease for compliance with district policy.**
  - Manage any concerns raised by the student, family, school nurse or teachers
- **Respect the student's confidentiality and right to privacy.**



# School Administrators, Staff, and Other Personnel – Putting Recommendations into Practice

## PRINCIPALS AND SCHOOL ADMINISTRATORS

*Please distribute to the superintendent, 504/IEP coordinator, or other school administrators responsible for coordinating student health services on a district wide level.*



- **Understand and ensure compliance with the federal and state laws** that apply to students with celiac disease. Understand the procedures for implementing laws including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Learn about celiac disease and the gluten-free diet.**
  - Attend a training seminar and review the provided documents. These seminars and materials are available free of charge at <https://www.openpediatrics.org>.
- **Participate in developing and implementing school policy related to celiac disease management at school.** This includes:
  - Working with food service providers to obtain gluten-free food options that are safe from cross-contact
  - Evaluating school-wide policies regarding food in the classroom and school-sponsored events

- **Identify all staff who have responsibility for students with celiac disease throughout the school day and during school-sponsored extracurricular activities and field trips.**
  - Work with the school nurse or health aide to implement the appropriate level of training for staff and to provide copies of the students' 504 Plans. This includes:
    - Food service providers
    - Teachers educating students with celiac disease
    - Volunteers participating in classroom activities
    - Counselors and mental health professionals providing support students with celiac disease
    - School nurses/health aide providing medical support for students with celiac disease
    - Building services staff
- **Inform all school staff and substitute teachers who supervise students with celiac disease about the needs of each child.** This includes:
  - Playground and cafeteria monitors
  - Lunchroom personnel
- **Develop and implement a system to prepare for the enrollment of a student with celiac disease.** This includes:
  - Preparing relevant documents for the family to convene a 504 Plan meeting
  - Information about how the school will accommodate a gluten-free diet
  - Information about how the school will keep the child safe from contact with gluten
- **Participate in meetings with the school health team, families and all staff who are responsible for students with celiac disease.**
  - Plan to schedule and attend a meeting of the school health team to discuss accommodations for each student:
    - Before the school year starts
    - When a student is newly diagnosed
    - Other times as deemed appropriate
- **Allocate sufficient resources for helping students with celiac disease in the school setting.** (e.g., gluten-free food and classroom materials).
- **Include gluten-free provisions for students with celiac disease in emergency/disaster planning if required to by state law.** (e.g., lockdown or evacuation).
- **Continue to work with the school health team to ensure implementation of the student's accommodations.**
  - Monitor compliance with these plans
  - Manage any concerns raised by the student, family, school nurse or teachers
- **Support and facilitate ongoing communication** among all members of the student's school health team.
- **Respect the student's confidentiality and right to privacy.**

## CLASSROOM TEACHERS AND TEACHING ASSISTANTS

Please distribute to classroom teachers, teaching assistants, substitutes, aids, volunteers, and other personnel who supervise or interact with children with celiac disease.



- **Understand and be knowledgeable about federal and state laws that apply to children with celiac disease,** including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, and the procedures for compliance with these laws.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Participate in the school health team meeting(s).** The teacher who has primary responsibility for the student should participate in the school health team meeting(s) when the student's health care plans (**Individualized Healthcare Plan and Section 504 Plan**) are discussed.
- **Provide a supportive and inclusive learning environment for students with celiac disease.** This includes providing students with:
  - Gluten-free food and supplies for all learning activities
  - Bathroom privileges, upon request
  - Access to school health personnel if symptoms occur
  - Handwashing with soap and water before eating
  - Tables and/or desks for eating cleaned with approved solutions
  - Safe participation in all school-sponsored learning and social activities
- **Identify all staff who have responsibility for students with celiac disease throughout the school day and during school-sponsored extracurricular activities and field trips.**
  - Work with the school nurse or health aide to implement the appropriate level of training for staff and to provide copies of the students' 504 Plans. This includes:
    - Food service providers
    - Teachers educating students with celiac disease
    - Volunteers participating in classroom activities
    - Counselors and mental health professionals providing support students with celiac disease
    - School nurse/health aide providing medical support for students with celiac disease
    - Building services staff
- **Recognize that reading ingredient labels on classroom materials and food items is a critical component of celiac disease management.** Gluten is found in many surprising items (e.g., Play-Doh®, paper mâché, finger paints). Double-checking of labels before exposing a student is crucial to his or her safety.
- **Recognize that students with celiac disease are like any other students in the class, except when it is necessary to respond to their medical needs and any resulting educational needs.** Be alert for teasing and bullying of the student with celiac disease due to peers' curiosity and lack of information about the gluten-free diet.
- **Recognize that a change in the student's behavior** could be a symptom of a gluten exposure. Report behavior changes to the school nurse/health aide and parents/guardians immediately upon awareness.

- **Know your role in helping a student with celiac disease during a gluten exposure.** This may include:
  - **Contacting** the student’s parents/guardians immediately
  - Seeking further **medical attention** if the student vomits continuously or appears severely dehydrated
  - Working with a designated staff member to **review the gluten exposure and response to the exposure** with the student’s parents/guardians to develop a strategy to prevent future exposures
- **Notify the parents/guardians in advance of any changes regarding food in the school schedule,** such as class parties, field trips, food-related lesson plans, and other special events.
- **Provide information for substitute teachers** about the day-to-day needs of the students with celiac disease. Consider providing a copy of this document to the substitute teacher.
- **Provide information to class parents and/or other learning environment volunteers about the needs of students with celiac disease** and request that any activities involving food or other materials/supplies be designed to allow for safe participation for a student with celiac disease.
- **Consult with the school nurse/health aide and the principal to determine the appropriate level of celiac management training** you should attend for carrying out your responsibilities. This training is available free of charge at <https://www.openpediatrics.org>.
- **Review the provided information about celiac disease** and refer to it, as needed, to help the students with celiac disease.
- **Communicate with the school nurse/health aide and parents/guardians regarding the student’s progress** or any other concerns about the student.



## SCHOOL NURSES/HEALTH AIDE

*In most learning environments, the school nurse or health aide is the key staff member who leads and coordinates health services and accommodations for a child with celiac disease in the classroom and learning-related activities. The school nurse or health aide should work in collaboration with the principal in identifying, training, and providing ongoing supervision for the child with celiac disease.*

*Please distribute to the school nurse.*



- **Understand and be knowledgeable about your responsibilities under federal and state laws that apply to children with celiac disease**, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, and the procedures for implementing these laws.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Receive in-depth training on celiac disease and the gluten-free diet.** These trainings are available free of charge at <https://www.openpediatrics.org>.
- **Plan and implement celiac disease and gluten-free diet training** for all staff members who have responsibility for a child with celiac disease.
- **Work to develop the Celiac Disease Management Plan** with the child's parents/guardians, including obtaining a diagnosis letter from the child's medical provider that includes documentation of symptoms and required care.
- **Review the provided information about celiac disease** and refer to it, as needed, to help the student with celiac disease.
- **Facilitate the school health team meeting(s)** to discuss implementing the child's Celiac Disease Management Plan. Participate as a health expert on the team.
- **Monitor adherence to the Celiac Disease Management Plan** and facilitate follow-up meetings to discuss any issues and concerns, provide updates, and evaluate the need for changes to the plan.
- **Ensure that all personnel mentioned in the Celiac Disease Management Plan have received training and are confident in carrying out their roles** to manage the child with celiac disease.
- **Work with other members of the school health team to build a supportive and inclusive learning environment** for students with celiac disease.
- **Maintain accurate documentation of all care** provided at the learning environment.
- **Provide ongoing training throughout the year** for current staff, new staff, and when there are changes to the Celiac Disease Management Plan.
- **Promote a supportive and inclusive learning environment and treat students with celiac disease the same as other students, except when necessary to respond to their medical needs.** Be alert for teasing and bullying of the student with celiac disease due to peers' curiosity and lack of information about the gluten-free lifestyle.
- **Provide educational materials and serve as a resource for managing celiac disease** for children, families and community members.
- **Act as an advocate for children with celiac disease** in the learning environment to help them meet their health care needs.
- **Assist classroom teachers with developing a plan and materials** for substitute teachers.

- Collaborate with the learning environment’s food service provider and/or the district’s dietitian/nutritionist to ensure safe gluten-free food options are provided for children with celiac disease.
- Network with outside organizations (e.g., hospitals, advocacy groups, professional societies, etc.) to receive the latest information on managing celiac disease in learning environments.
- Know your role in helping a student with celiac disease after a gluten exposure. This may include:
  - Contacting the child’s parents/guardians immediately
  - Seeking further medical attention if the child vomits continuously or appears severely dehydrated
  - Reviewing the gluten exposure and response to the exposure with the child’s parents/guardians to develop a strategy to prevent future exposures



## SCHOOL PSYCHOLOGISTS AND COUNSELORS

Please distribute to the psychologist, counselor, and/or social worker.



- **Understand and be knowledgeable about federal and state laws that apply to children with celiac disease**, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, and the procedures for implementing these laws.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Consult with the school nurse/health aide and the principal to determine the appropriate level of celiac disease management training** you should attend for carrying out your responsibilities. This training is available free of charge at <https://www.openpediatrics.org>.
- **Review the provided information about celiac disease** and refer to it, as needed, to help the student with celiac disease.
- **Participate in the school health team meeting(s)** and communicate with the school nurse/health aide and parents/guardians regarding any concerns about the student.
- **Work with other members of the school health team to build a supportive and inclusive learning environment** for students with celiac disease. Advocate for curriculum adjustments that may be needed while not compromising learning goals.
- **Recognize that students with celiac disease are like any other students in the class, except when it is necessary to respond to their medical needs and any resulting educational needs.** Be alert for teasing and bullying of the student with celiac disease due to peers' curiosity and lack of information about the gluten-free diet.
- **Be aware of and prepared to respond to emotional needs of students with celiac disease.** Every child responds differently to a diagnosis of celiac disease. Some are accepting right away and adjust easily to the gluten-free diet. Others are resentful. Be aware of the child's feelings about having celiac disease and identify strategies to support their learning experience to minimize exclusion from learning environment activities.
- **Recognize that students with celiac disease may at times rebel and discontinue strict adherence to the gluten-free diet.** Identify strategies to support the daily demands of the gluten-free diet by working with both the child and the parents/guardians.
- **Recognize that a change in the student's behavior** could be a symptom of a gluten exposure.
- **Be aware of signs of disordered eating**, such as unexplained weight loss, restrictive eating, social isolation, and binge eating. Report suspected disordered eating to the school nurse/health aide and parents/guardians immediately upon awareness.
- **Know your role in helping a student with celiac disease after a gluten exposure.** This may include:
  - **Contacting** the child's parents/guardians immediately
  - Seeking further **medical attention** if the child vomits continuously or appears severely dehydrated
  - **Reviewing the gluten exposure and response to the exposure** with the child's parents/guardians to develop a strategy to prevent future exposures
- **Work with other members of the school health and administration team to implement** the student's health care and accommodation plans, including who may have access to the plans based upon relevant privacy protections and parent/guardian preferences.
- **Make students with celiac disease aware of your availability and accessibility** within learning environment setting to address their emotional needs related to their disease.

## SCHOOL FOOD SERVICE MANAGERS AND STAFF

Please distribute to the food service managers and staff.



- **Understand your own and your staff's responsibilities under federal and state laws** that apply to students with celiac disease. Understand the procedures for implementing laws including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Learn about celiac disease and the gluten-free diet.**
  - Attend a training seminar and review the accompanying documents. These seminars and materials are available free of charge at <https://www.openpediatrics.org>.
  - **Identify students who require gluten-free food accommodations** in a way that does not compromise their privacy or confidentiality rights.
- Some children with celiac disease have multiple food sensitivities (e.g., gluten, dairy, soy). **Ensure that for each student requiring gluten-free food accommodations that you and the staff review and understand the physician's diagnosis statement** and account for all required food substitutions.
- **Understand how to read food labels to identify gluten in foods and beverages served during meal times.** If additional information is needed, contact the food manufacturer to clarify a product's ingredients.
- **Support implementation of school policy.** Ensure you and your staff work with the school health team to provide gluten-free accommodations in the cafeteria including:
  - Purchasing gluten-free food options that meet the FDA definition of gluten-free.
  - Preparing gluten-free food that is free of cross-contact with gluten.
  - Designating food preparation space that is free of gluten.
  - Implementing systems to prevent cross-contact with gluten while serving gluten-free foods.
  - Obtaining and sharing ingredients with the student and family as requested.
- **Provide breakfast and lunch menus and/or a meal schedule at least one week in advance to the student's parents/guardians.**
  - Designate gluten-free substitutions for menu items where necessary.
  - Advise the family of any unannounced menu substitutions.
- **Provide input to the school health team when requested.**
- **Communicate with the school nurse/health aide regarding any concerns with the student's progress or adherence to cafeteria accommodations.**
- **Help teachers using food in lessons to read food labels and select gluten-free options.**
- **Promote a positive psychosocial environment in eating spaces** by encouraging supportive and positive interactions between students. Reinforce rules against bullying and discrimination. Report any incidents of bullying or discrimination involving a student with celiac disease.
- **Work with school administrators to effectively communicate policies and practices regarding gluten-free food service** to parents and students through newsletters, announcements, bulletins, and other methods used to communicate with the school community.

## FACILITIES AND MAINTENANCE STAFF

Please distribute to the facilities and maintenance staff including custodians.



- **Understand your own and your staff's responsibilities under federal and state laws** that apply to students with celiac disease. Understand the procedures for implementing laws including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.
  - **A child with celiac disease should have a 504 Plan** in place. While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Learn about celiac disease and the gluten-free diet.**
  - Attend a training seminar and review the accompanying documents. These seminars and materials are available free of charge at <https://www.openpediatrics.org>.
- **Identify students or learning environment areas that require preventative cleaning measures to minimize gluten cross-contact** that does not compromise the students' privacy or confidentiality rights..
- **Support implementation of school policy.** Ensure that you and your staff work with the school health team to minimize exposure to gluten by:
  - Cleaning floors, surfaces, and food handling areas with soap and water or approved all-purpose cleaning products.
  - Enforcing district food policies as they relate to sanitation.
- **Provide input to the school health team when requested.**
- **Promote a positive psychosocial environment in eating spaces** by encouraging supportive and positive interactions between students. Reinforce rules against bullying and discrimination. Report any incidents of bullying or discrimination involving a student with celiac disease.
- **Work with school administrators to effectively communicate policies and practices regarding cleaning protocols.**



# Parents/Guardians and Families – Putting Recommendations into Practice

*Please distribute to parents/guardians of children with celiac disease.*



- **Notify your child’s school principal, as well as the school nurse/health aide, school psychologist or guidance counselor and teacher(s) that your child has celiac disease** when the student enrolls in school, is newly diagnosed with the condition, and at the beginning of each school year.
- **Work with your child’s celiac disease health care team to develop a Celiac Disease Management Plan** (This might be a 504 Plan depending on the learning environment).
- **Permit sharing of medical information** necessary for your child’s safety between the learning environment and your child’s health care providers.
- **Provide accurate and current emergency contact information** to the learning environment and update with any changes.
- **Attend and participate in the initial and annual meetings of the school health team to discuss implementing the requested accommodations** in your child’s Celiac Disease Management Plan and to review the services your child may need.
- **Understand and be knowledgeable about federal and state laws that apply to children with celiac disease**, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, and the procedures for implementing these laws.
  - **A child with celiac disease should have a 504 Plan in place.** While an Individual Health Plan (IHP) may be appropriate for some children with celiac disease, the IHP does not replace the need for a 504 Plan. If the child has an existing Individual Education Plan (IEP) in place, accommodations for celiac disease may be documented within the existing plan or within an accompanying IHP.
- **Review the information in the Voluntary Recommendations for Managing Celiac Disease in Learning Environments** to work effectively with your child’s learning environment team.
- **Inform the school nurse/health aide or other designated staff about any changes** in your child’s health or celiac disease symptoms.
- **Provide all supplies to the learning environment that are considered parent-supplied under the Celiac Disease Management Plan.** These may include gluten-free snacks, treats for celebrations, materials for classroom projects, among others.
- **Inform appropriate staff when your child plans to participate in learning environment-sponsored activities that take place before or after school, or off campus** so that appropriate accommodations are provided.
- **Discuss privacy and confidentiality rights with your child and communicate their preferences** to learning environment officials regarding disclosure of their diagnosis to other students.



# Sample Letter Explaining Celiac Disease to Other Parents and Parent Teacher Organizations

June 10, 2019

Dear Class Parents:

There is a student in your child's class who has celiac disease. In a communal effort to foster inclusivity and emotional support for all children in our class, we want to share some information about celiac disease and ways you can help create an inclusive classroom for all of our children.

Celiac disease is a genetic autoimmune condition that affects the villi of the small intestine and prevents absorption of nutrients from food. Symptoms of celiac disease vary from one person to another, and some people with celiac disease may not have any symptoms at all. Individuals with asymptomatic celiac disease are still at risk for complications and related health problems because the same underlying intestinal damage occurs. Some of the more common symptoms in children include nausea, constipation, abdominal pain, skin rashes, headaches, joint pain, fatigue, or behavioral changes/mood disturbances.

The current treatment for celiac disease is a **strict gluten-free diet**, which means **avoiding all forms of wheat, rye and barley**. In addition to the foods being gluten-free, it is equally important that these foods are not contaminated by coming into contact with other gluten-containing foods during their preparation or service.

## Ways you can show support in the classroom environment:

- **When sending something in for a birthday or holiday celebration**, try choosing a naturally gluten-free option like ice cream or a non-food product when possible.
- If you are preparing food at home for school, **take care to avoid potential cross-contact with gluten**. Gluten-free foods should be prepared separately and with separate utensils from gluten-containing foods. To avoid any chance of cross-contact, consider purchased a packaged gluten-free product.
- There are **non-food items that contain gluten**, so it is important to be aware of these products as well if planning a class craft or activity. Some of these materials include Play-Doh®, Crayola™ Dough, Elmer's™ finger paints, Baker Ross® finger paints, gluten-containing pasta, and paper mâché. While there is no evidence to support that gluten is transmitted through skin, if products are placed in the mouth, exposure can occur. Handwashing after use of these materials is very important to remove any contact with gluten.

I hope that this brief overview of celiac disease and the gluten-free diet has helped you to better understand celiac disease and what you can do to show support for all students in our classroom. If you have any questions or concerns, please do not hesitate to contact me and I would be more than happy to provide additional education and/or resources.

Sincerely,

Pediatrician/Gastroenterologist  
Celiac Disease Program

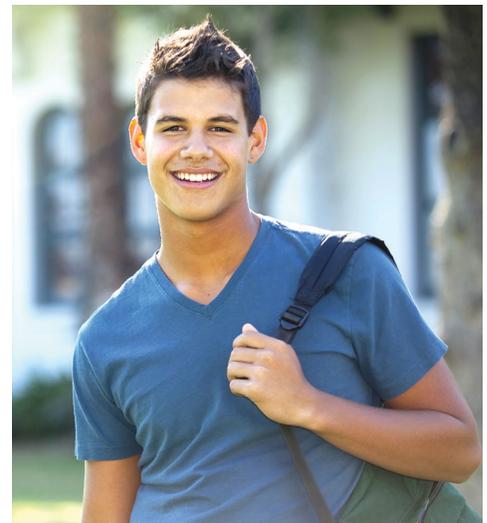
# Children with Celiac Disease – Putting Recommendations into Practice

Please distribute the age-appropriate action list to children with celiac disease.

## TEENS WITH CELIAC DISEASE WITH CELIAC DISEASE



- **Understand the requirements of maintaining a gluten-free diet including:**
  - Knowing the definition of gluten-free: avoiding all foods that contain wheat, rye and barley and any derivatives of these ingredients
  - Confidently reading a food label to identify gluten in food
  - Being able to explain how to prepare a gluten-free meal with no cross-contact with gluten
- **Find out who is on your learning environment health team** – these are the people who will help with managing your celiac disease and gluten-free diet at school. This might include your teacher(s), cafeteria staff, school nurse, school psychologist, and coach, among others.
- **Participate in all meetings with your health team to talk about your health and education plans.** This will ensure that you understand and agree with all of your accommodations.
- **Clearly understand:**
  - What **accommodations** you should be receiving throughout the school day
  - Whom to **contact** if you feel symptoms of a gluten exposure
  - Steps to take when you know you were exposed to gluten
- **If meals are provided by your school/learning environment**, be familiar with the process and procedures for getting your gluten-free food and know who to contact to assist you.
- **Tell your teacher or other school staff if you are having symptoms of a gluten exposure**, especially if you need help or support. Don't be ashamed or embarrassed to ask for help.
- **Take ownership of your celiac disease at school.** Ask questions if you feel something is not safe and don't eat anything that you suspect contains gluten.
- **Share information about your celiac disease and gluten-free diet with your friends and peers** as you feel comfortable.



## CHILDREN AGES 7-12 WITH CELIAC DISEASE



- **Understand the requirements of maintaining a gluten-free diet including:**
  - Knowing the definition of gluten-free: avoiding all foods that contain any form of wheat, rye and barley
  - Being able to find a gluten-free label on a food package
  - Identifying the words wheat, rye, and barley on a food label
  - Explaining that any food you eat must be prepared with no cross-contact with gluten
- **Find out who is on your learning environment health team** – these are the people who will help with managing your celiac disease and gluten-free diet at school. This might include your teacher(s), cafeteria staff, school nurse, school psychologist, coach, among others.
- **Participate in all meetings with your health team to talk about your health and education plans.** This will ensure that you understand and agree with all of your accommodations.
- **Clearly understand:**
  - What **accommodations** you should be receiving throughout the school day
  - Whom to **contact** if you feel symptoms of a gluten exposure
  - Steps to take when you know you have been exposed to gluten
- **If meals are provided by your school/learning environment,** be familiar with the process and procedures for getting your gluten-free food and know who to contact to assist you.
- **Tell your teacher or other school staff if you are having symptoms of a gluten exposure,** especially if you need help or support. Don't be ashamed or embarrassed to ask for help.
- **Take ownership of your celiac disease at school.** Ask questions if you feel something is not safe and don't eat anything that you suspect contains gluten.
- **Share information about your celiac disease and gluten-free diet with your friends and peers** as you feel comfortable.

## CHILDREN AGES 3-6 WITH CELIAC DISEASE



- **Understand basic information about your diagnosis and the gluten-free diet.**
  - You were diagnosed with celiac disease.
  - You can only eat food that is gluten-free.
  - Wheat, rye, and barley will make you sick.
  - You cannot put gluten in your mouth.
  - You can touch gluten, but you must wash your hands afterwards. You should wash your hands with soap and water while singing happy birthday.
- **Find out who is on your health team** – these are the people who will help with managing your celiac disease and gluten-free diet. This might include your teacher(s), cafeteria staff, nurse, and psychologist, among others.
- **Clearly understand:**
  - **Who to tell** if you feel sick.
  - What to do if you **think you ate gluten.**
- **If you eat at your learning environment,** know who to ask to get your gluten-free food.
- **Tell your teacher if you are not feeling well.** It is ok to tell them if you feel sick or need help.
- **Take ownership of your celiac disease at school.** Ask questions if you feel something is not safe and don't eat anything that you think has gluten in it.
- **Tell your friends about your celiac disease and gluten-free diet** if you want them to know.

## Physicians, Nurses, Psychologists and Other Health Professionals

*Please distribute to health care professionals caring for children with celiac disease.*



- **Keep up to date with federal and state laws that may apply to students with celiac disease** including Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Food Allergen Labeling and Consumer Protection Act, and the FDA Gluten-Free Food Labeling Rule. (See Federal Laws that Govern Celiac Disease in Learning Environments)
- **Direct patients and families to "Recommendations for Management of Celiac Disease at School"** to assist with the development of a Celiac Disease Management Plan.
- **Provide a signed letter confirming celiac disease diagnosis**, explaining celiac disease and outlining the basic requirements for maintaining a gluten-free diet. (See Sample Diagnosis Letter)
- **Review accommodation plan** with patient and family at follow-up visits to ensure adherence to the gluten-free diet.
- **Direct patients and families to notify the provider** when the Plan has been implemented and if any hurdles are encountered during implementation.
- **Communicate with educators and/or other school personnel as needed** if questions or issues arise.
- **Educate referring pediatricians and others within the physician community** about celiac disease and accommodations under Section 504.



# RESOURCE DOCUMENTS

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- Sample Letter Explaining Celiac Disease to Class Parents ..... 40
- Gluten-Free Safe, Unsafe, and Questionable Foods List..... 41
- Gluten-Free Tips for the Cafeteria..... 43
- Preventing Cross-Contact of GF Foods ..... 45
- Simple Classroom Substitutions ..... 47
- Home Economics and Cooking Class Modifications ..... 48
- Gluten-Free School Supply List..... 49
- Gluten-Free Ingredients Glossary ..... 51

# Sample Diagnosis Letters for Schools

September 12, 2017

To Whom It May Concern:

Brandon Smith DOB 9/24/13 is a patient in the Division of Gastroenterology, Hepatology and Nutrition at Children's National Hospital. In August 2017, Brandon was diagnosed with celiac disease, a genetic autoimmune condition that affects the villi of the small intestine. The diagnosis was made via both blood screening and small bowel endoscopy.

At the time of diagnosis, Brandon's primary symptoms were diarrhea, vomiting and severe anemia caused from his body's inability to absorb nutrients from the food he ate. While these were his principal symptoms at diagnosis, it is well known that over time symptoms of celiac disease change and he may experience additional symptoms upon gluten exposure including nausea, constipation, abdominal pain, skin rashes, headaches, joint pain, fatigue, or behavioral changes/mood disturbances.

The only current treatment for celiac disease is a **strict gluten-free diet**, which means avoiding all forms of **wheat, rye and barley**. In addition to the foods being gluten-free, it is equally important that these foods are not contaminated by coming into contact with other gluten-containing foods during their preparation or service. Please see the attached safe, unsafe and questionable food charts.

Gluten is also found in everyday school supplies including Play-Doh®, finger paints, paper mâché, and sensory table objects. While there is no evidence to support that gluten is transmitted through skin, if these gluten-containing products are placed in the mouth, exposure can occur. If Brandon uses a gluten-containing material, it is important for him to **wash his hands thoroughly and have the table workspace cleaned as well**.

Inadvertent or accidental ingestion of gluten **affects a student's ability to learn and seriously endangers the student's health**, both immediately and in the long term. Regular exposure to gluten can lead to complications including malnutrition, auto-immune thyroiditis, liver disease, osteopenia, osteoporosis, infertility, neurological conditions, and, in rare cases, cancer (lymphoma), and permanent immunological scarring.

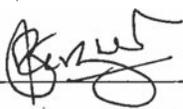
Cross-contact (i.e., gluten-free foods being contaminated by gluten-containing foods) must always be considered. Gluten containing foods should be prepared separately and with separate utensils from gluten-free foods.

It is not necessary to separate Brandon from other students while food is being eaten, however, special care must be made to avoid cross-contact during food preparation and serving. And of course, please always encourage good hand hygiene to prevent cross-contamination from child to child. **If accidental gluten-ingestion occurs, it is not a medical emergency, but please inform Brandon's parents of the exposure.**

Lastly, please allow Brandon to use the restroom and/or visit the school nurse's office if he should experience abdominal pain or any other symptom of a gluten exposure.

I hope that this brief overview of celiac disease and the gluten-free diet has helped you to better understand Brandon's diagnosis, and I appreciate all that you do in the school environment to help keep him healthy. If you have any questions or concerns, please do not hesitate to contact me and I would be more than happy to provide additional education and/or resources.

Thank you,

  
A handwritten signature in black ink, appearing to read "Benny Kerzner", is written over a horizontal line.

**Dr. Benny Kerzner**

Medical Director, Celiac Disease Program | Children's National Hospital | [bkerzner@childrensnational.org](mailto:bkerzner@childrensnational.org)

# The Gluten-Free Diet: A Basic Overview of Food

## Celiac School Action Guidelines for Education



Gluten is a protein found in all forms of wheat, rye, and barley. It is most commonly found in food, but it also hides in medicine, vitamins, and makeup. The first thing anyone should do when starting a gluten-free diet is schedule a meeting with a skilled dietitian or nutritionist. A well-trained professional can help teach the basics of a gluten-free diet and help find ways to adapt to the new lifestyle.

When at home or at the grocery store, a quick guide to ingredients can be a helpful tool for quickly determining if a packaged product is safe.

### Gluten-Free Ingredients

Eliminating wheat, barley, and rye from a diet may seem like a daunting task, but it's important to remember that there are still hundreds of grains and other foods that can be eaten. Staples like fresh fruits and vegetables, meats, poultry, seafood, and most types of dairy are all gluten-free in their natural forms. Examples include the following:

Acorn Flour	Calrose	Cornstarch	Hominy	Potato Starch	Sunflower Seeds
Almond Flour	Canola	Cottonseed	Instant Rice	Quinoa	Sweet Rice Flour
Amaranth	Cassava	Dal	Kasha	Red Rice	Tapioca
Arborio Rice	Channa	Dasheen Flour	Lentils	Rice Bran	Tapioca Flour
Arrowroot	Chestnut	Enriched Rice	Millet	Rice Flour	Taro Flour
Baker's Yeast	Chickpea Flour	Fava Bean	Modified Corn	Risotto	Teff
Basmati Rice	Coconut Flour	Flax	Starch	Sago	Tofu
Bean Flours	Corn	Flax Seeds	Modified Tapioca	Sesame	White Rice Flour
Brown Rice	Corn Flour	Garbanzo	Montina	Sorghum	Xanthan Gum
Brown Rice Flour	Corn Gluten	Glutinous Rice	Peanut Flour	Soy	Yeast
Buckwheat	Corn Meal	Guar Gum	Potato Flour	Soybeans	Yuca

### Gluten-Free Food Additives

When purchasing packaged foods, there will likely be many ingredients listed that sound unfamiliar or strange. Below is a list of food additives that are safe for a gluten-free diet:

Acacia Gum	BHA	Carob Bean Gum	Fumaric Acid	Malic Acid	Pectin
Adipic Acid	BHT	Cellulose	Gelatin	Maltodextrin	Polysorbate
Algin	Brown Sugar	Corn Syrup	Glucose	Maltol	Propylene Glycol
Annatto	Calcium	Cream of Tartar	Invert Sugar	Mannitol	Psyllium
Aspartame	Disodium	Dextrose	Karaya Gum	Methylcellulose	Sodium Benzoate
Baking Yeast	Carrageenan	Distilled Vinegar	Lactic Acid	Monosodium	Sodium
Benzoic Acid	Caramel Coloring	Ethyl Maltol	Lactose	Glutamate	Metabisulphite
Beta Carotene	Carboxymethyl	Fructose	Lecithin	Papain	Sodium Nitrate

(over)

## Gluten-Free Food Additives *(continued)*

Sodium Sulphite	Stearic Acid	Tartaric Acid	Vanilla Extract	Autolyzed Yeast
Sorbitol	Sucralose	Tartrazine	Xylitol	Extract
Spices (100 percent pure)	Sucrose	Titanium Dioxide	Yam	Nutritional Yeast
	Sugar	Vanilla Bean	Yeast; Autolyzed	

## Gluten-Containing Foods

Below is a list of basic food items that contain gluten. It's important to note that this is **not a complete list of gluten-containing foods**. If ever unsure about the safety of a product, call the manufacturer directly.

Barley	Bulgur	Farina	Macha	Rice Malt	Triticale
Barley Extract	Bulgur Wheat	Fu	Malt	Rye	Wheat
Barley Grass	Croutons	Graham	Malt Flavoring	Seitan	
Barley Malt	Couscous	Hordeum Vulgare	Malt Syrup	Spelt	
Barley Pearls	Durum	Hydrolyzed	Malt Vinegar	Semolina	
Bran	Einkorn	Wheat Protein	Matzo	Sprouted Wheat	
Bleached Flour	Emmer	Kamut	Mir	Tabbouleh	

## Questionable Foods and Products

There are many food items that appear on grocery store shelves that may or may not contain gluten. Unfortunately, because of varied manufacturing processes, it is impossible to generalize about any of these products. The only way to ensure one of these products is in fact safe is to check the food label or contact a manufacturer directly. Below is a list of questionable products that must be double-checked.

- Beer (all forms are unsafe except those labeled gluten-free)
- Beef/Chicken/Fish/Vegetable Stock (may contain wheat)
- Bouillon (may contain wheat)
- Brewer's Yeast (depends on whether it's a by-product of the brewing process [unsafe] or made from sugar beets [safe])
- Dextrin (could be made from wheat, corn, potato, arrowroot, rice or tapioca)
- Fillers (could be wheat, corn, potato or other starch)
- Lipstick/Lip Gloss/Lip Balm (may contain wheat or barley)
- Malted Grains (any grain can be malted. For example, gluten-free beer manufacturers use malted sorghum as an ingredient. This is considered safe. A malted grain would be unsafe if the malted ingredient is wheat, rye or barley)
- Marinades (may contain wheat)
- Miso (may contain barley)
- Multivitamins/supplements (may contain wheat starch)
- Mustard Powder (may contain wheat)
- Oats (may be contaminated due to storage and transportation methods)
- Play-Doh® (may contain wheat)
- Rice Syrup (could be made using barley)
- Soy Sauce (may contain wheat)
- Spices (combination spices may contain wheat)
- Toothpaste (dental products may have malted products in their additives and stabilizers)
- Yellow Mustard (may contain wheat)
- Yogurt, flavored (may contain dextrin or barley extract)
- Wheat Starch: if the label specifies certified gluten-free wheat starch, the product meets the definition of gluten-free.

# Gluten-Free Tips for the School Cafeteria

Celiac School Action Guidelines for Education



## Tips for Gluten-Free Protocols in School Cafeterias

While there are many ways to approach setting up a gluten-free protocol, below are some areas that every cafeteria should consider modifying.

### Salad or Sandwich Bar

Fresh fruits, proteins, and vegetables are key ingredients in a gluten-free diet, making a salad or sandwich bar the perfect place for students with celiac disease to find safe and healthy foods. However, cross-contact on these bars can become a big safety issue if gluten-containing ingredients are improperly placed on the bar. To keep a salad and sandwich bar safe for gluten-free students, keep the following protocols in mind when setting the bar up each day:

- Always place gluten-containing ingredients like bread, croutons, pita chips, and crackers at the far end of the bar so they are set away from the fresh vegetables, proteins, and fruits.
- Keep gluten-free bread separate from traditional wheat bread to prevent confusion and contamination.
- Place gluten-containing products in the front row of the salad bar so students do not need to drag them over the top of gluten-free ingredients to access them if both must be near each other. This will greatly reduce the risk of cross-contact.
- Always serve salad dressing in squeeze bottles so the dressing never comes in contact with gluten-containing foods.

*(over)*

## Squeeze Bottles for Condiments

Always use squeeze bottles for condiments like ketchup, mustard, mayonnaise, salad dressings, sauces, relish, and chocolate sauce. Squeeze bottles prevent cross-contact and allow all students to use the same condiment products without concern for double dipping.

## Pantry Organization

When setting up the storage pantry, always store gluten-free ingredients on top of gluten-containing ingredients to prevent gluten-containing particles from falling into the gluten-free products.

## Base Products

Most cafeterias use soup and sauce bases that contain gluten. The most common are products that use wheat flour as a thickening agent. Here are a few ways to easily adjust items so all students can enjoy the same foods:

- **Soup and sauce bases:** Order bases that use cornstarch, tapioca starch, or arrowroot as the thickener. There will be no discernable difference in taste or price. By making this small modification, all students will be able to enjoy the same foods.
- **Chips:** Simply order corn chips instead of wheat-based tortilla chips. The price may actually go down because of this change. For taco days, use corn tortillas instead of flour tortillas.
- **Pasta in soups:** When making chicken noodle or minestrone soup, for example, do not put the noodles into the soup until the students order each bowl. This will allow gluten-free students to eat the vegetable-filled soups and broths safely without noodles. Or, set aside a portion of soup with no noodles for students who require a gluten-free option.

## Gluten-Free Specialty Items

Some schools make the decision to order specialty gluten-free items for students to eat at school, while others ask parents to supply these items themselves. The choice is up to each individual school, but here are a few things to keep in mind:

- Gluten-free students want to feel included, and an easy way to do this is by stocking specialty gluten-free items like pizza, pasta, bread, and cookies so they are regularly available. When the special of the day is pizza, simply cook a frozen gluten-free pizza for the gluten-free students. If the special is pasta, make a separate pot of gluten-free pasta in clean water for the gluten-free students to enjoy.
- Most suppliers now readily stock gluten-free items, and they can be added to the weekly order.
- Keep gluten-free bread in the freezer for the gluten-free student to regularly make sandwiches. A dedicated gluten-free toaster should be used for toasting.
- If the school asks parents to provide specialty gluten-free items, set up a regular communication system so the parents are aware of upcoming meals and can adequately provide products for their children.

## Communication is Key

Regardless if the school decides to supply gluten-free products or the parents are asked to supply them, the easiest way to ensure a smooth process is for everyone to understand how gluten-free foods will be served safely and how the student can access the food on a daily basis. Once the cafeteria has a plan for organization, be sure to set-up a meeting that includes the parents, student, and necessary school personnel to make sure that everyone has a clear understanding of how the child will obtain the food each day.

# Preventing Cross-Contact

## Celiac School Action Guidelines for Education



### Preventing Cross-Contact in Your Kitchen

## When on a gluten-free diet,

staying safe means avoiding any potential sources of cross-contact. This can happen very easily and unintentionally, so it is important to understand the many ways in which cross-contact can occur at home. While a household does not need to be entirely gluten-free in order to be safe, there are several measures that can be taken to ensure utensils, condiments, frying oil, boiling water, and food preparation surfaces are sterilized to remain safely gluten-free. It is not any more difficult than preventing against bacteria; just remember to keep kitchen elements clean.

- **BOILING WATER:** Gluten-free pasta and gluten-containing pasta **cannot** be cooked in the same water. Gluten from the gluten-containing pasta will contaminate the water and make those with celiac disease sick. The same applies to cooking gluten-free items such as quinoa, rice, vegetables, or potatoes in boiling water that has already come into contact with gluten-containing ingredients. Additionally, if the food being prepared requires straining, be sure that only gluten-free items go into one strainer while gluten-containing foods are strained in a separate colander, or be sure gluten-free foods are strained first.
- **CONDIMENTS:** Any condiment that it is used as a dip with a utensil should not be used with both gluten-free and gluten-containing foods. Particles from gluten-containing ingredients easily contaminate jars of peanut butter, cream cheese, butter, etc. that were dipped in it. To be extra cautious, in a mixed gluten household, consider buying separate condiments and labeling one set as gluten-free. Those eating gluten-free foods should only use the gluten-free set of condiments. Otherwise, have a conversation with the family and/or housemates about scooping out a portion of the item onto a plate before spreading it onto the gluten-containing item to ensure only a clean knife has been dipped into the container once. For other condiments like ketchup, mustard, mayonnaise, and relish, consider buying squeeze bottles to prevent cross contamination from dipping into the containers.
- **CUTTING BOARDS:** Thoroughly scrubbing a plastic or glass cutting board before and after each use makes it completely safe to share with gluten-free and gluten-containing items, assuming they're not being used at the same time. However, it often helps to have two sets of cutting boards in the kitchen to be absolutely safe.

(over)

Consider picking a different color cutting board for the gluten-free set, so families can easily identify which board is safe to use. It also is the safest to use plastic or glass cutting boards whenever possible. Wooden cutting boards can absorb foods like gluten, and in turn, could lead to cross-contact even after washing.

- **FRYING:** Never fry gluten-free and gluten-containing items in the same oil. Particles from the gluten-containing items will fall into the oil and contaminate the gluten-free foods. Even if the oil looks clean, don't trust it. Always use clean oil for gluten-free foods. This issue is particularly important in restaurants. When ordering fried foods, always ask if the restaurant uses separate oil for gluten-free and gluten-containing items.
- **POTS AND PANS:** Always wash pots and pans thoroughly between each use. As long as they are washed properly, it is safe to cook both gluten-free and gluten-containing items in the same pots and pans. Think of it this way: if pots and pans are washed well enough to prevent food-borne bacteria from spreading, then they also are sufficiently cleaned to prevent gluten contamination.
- **SHELVES AND DRAWERS:** Consider designating space within the kitchen storage areas for gluten-free foods. This will help to visually separate the items that need to be kept free of cross-contact. If gluten-free and gluten-containing items must be in the same shelves and drawers, always store the gluten-free products above the gluten-containing items. This method will prevent gluten particles from falling into the gluten-free products.
- **TOASTING:** Crumbs quickly accumulate in every toaster. There is no way to prevent it. Bread crumbles and creates a massive problem for cross-contact. If using a **toaster oven** that is thoroughly cleaned between each use, there is no reason to have separate toasters. Another option for using a toaster oven is to **always** line the racks with foil when toasting gluten-free items. This will prevent cross-contact and limit the in-between-use cleaning. However, if using a **pop-up toaster** that is unable to be easily cleaned out, it's recommended to have a designated gluten-free toaster.
- **METAL OR PLASTIC UTENSILS:** As with each and every other piece of kitchen equipment, the same metal or plastic utensils cannot be used with gluten-free and gluten-containing items without a thorough cleaning. Either make the decision to always wash the utensils in between use or purchase a second set of designated gluten-free items.



## Simple Classroom Substitutions

There are many very simple substitutions that can be made to make learning activities safe for all children.

### Sensory tables

Use rice, dried corn, and beans or gluten-free pasta.

### Art Classes

**Crafts** - Use gluten-free pasta, make collages with naturally gluten-free ingredients like rice, quinoa, corn, beans, etc.

**Play-Doh®** - Use alternatives (Crayola®) or homemade modelling dough made from rice flour and cornstarch.

Make **paper mâché** using corn starch or rice flour.

### Science Projects

Try naturally gluten-free projects (grow rock candy crystals, emulsify with oil/vinegar, make your own bubbly water drink, methods for making butter, etc.).

### Cooking with Kids

Try naturally gluten-free recipes.

Select a naturally gluten-free all-purpose flour for all children to use (see gluten-free flours and grains guide).

## Home-Economics and Cooking Class Suggestions

Home economics and cooking classes are environments where children with celiac disease are exposed to gluten. However, with a few adjustments, learning environments can create an inclusive classroom that allows students living a medically necessary gluten-free diet to participate in **ALL** food-related activities. Here are some suggested modifications:

Select **naturally gluten-free** recipes.

Substitute **gluten-free ingredients** in recipes utilizing items like flour, pasta or pizza crusts. Gluten-free versions of these ingredients are readily available in all mainstream grocery stores. Some suggested brands include:

King Arthur Measure for Measure Flour	Schar Gluten-Free	Kikkoman Panko Gluten-Free Bread Crumbs	Schar Gluten-Free	Mission Gluten-Free
Bob's Red Mill One-to-One Flour	Udi's Gluten-Free	Ians Gluten-Free Panko Bread Crumbs	Barilla Gluten-Free	Udi's Gluten-Free
Pamela's Products All-Purpose Artisan Flour Blend	Against the Grain	Simply Balanced Gluten-Free Crumbs	Ronzoni Gluten-Free	Siete Cassava & Coconut Tortillas
Cup 4 Cup Gluten-Free Flour	Gillian's Pizza Dough	4C Gluten-Free Crumbs	Ancient Harvest	La Tortilla Factory

Provide a **thoroughly-cleaned cooking station**, with clean and sanitized equipment and utensils. Please follow required cleaning procedures that meet state and local standards.

Allow the student to choose partners or assign partners who are willing to cook gluten-free so the student is not cooking alone.

### Safety Measures to Consider

Shared pots, pans, cutting boards, and utensils can be safely used by a student with celiac disease. However, they must be scrubbed thoroughly with soap and water before use. Please use the same level of cleaning that you would use to clean kitchen utensils that have touched raw chicken. This same level of diligence will remove gluten.

Baking activities with loose flour can be an issue for a student with celiac disease. A study (**Miller, K., N. McGough, and H. Urwin. 2016. Catering glutenfree when simultaneously using wheat flour. J. Food Prot.79:282-287**) found that gluten-free food can be safely prepared in a shared commercial kitchen space where wheat-based flour is concurrently used provided:

Proper sanitation methods are followed (clean surfaces, equipment, and utensils)

The gluten-free station **is set up approximately 2 meters (6.56 feet) apart** from the area used for gluten-containing flours.

## Gluten-Free School Supply List

The following supplies are considered gluten-free and safe for a child with celiac disease to use in a learning environment.

### GLUE

All Elmer's™ glue products  
Colorations™ Washable School Glue

### GLUTEN-FREE MODELING CLAY RECIPE

Aroma Dough™  
Colorations™ Wheat and Gluten-Free Dough

### FINGER PAINT

Colorations™ Washable Finger Paint  
Crayola™ Washable Finger Paint



## GLUTEN-FREE MODELING CLAY RECIPE:

1 cup rice flour  
1 cup cornstarch  
1 cup salt  
4 teaspoons cream of tartar  
2 cups water  
2 teaspoons vegetable oil  
Food coloring or glitter of choice

In a nonstick pot, mix all ingredients together

Heat over low heat for 3 to 5 minutes until a ball forms.

Cool completely before using for play. Store in a resealable plastic bag

## GLUTEN-FREE PAPER MÂCHÉ RECIPE

1 cup corn starch  
1 tablespoon salt  
1 teaspoon cold water  
Boiling water

Combine corn starch and salt in a large bowl or tub.

Gradually add water until you get a runny slurry.

Add boiling water and mix together

Set to side and allow to cool.



# GLUTEN-FREE INGREDIENTS GLOSSARY

This detailed glossary identifies gluten-free flours, grains, and additives. Study it carefully to become an expert on gluten-free ingredient terminology.

**Acacia Gum:** Acacia gum is a natural gum consisting of the hardened sap of various species of the acacia tree. Also known as gum Arabic, it is soluble in water. It is edible and used primarily in the food industry as a stabilizer.

**Almond Flour:** Almond flour is a naturally gluten-free flour made from blanched whole almonds that have been ground into a fine powder. It's packed with protein and fiber which means using almond flour will help you feel full longer. (Per ¼ cup: 3g fiber and 4g protein). It will also help give your breads and muffins a soft texture. You can use almond flour as a one-to-one replacement in baking, but it's most often used as part of a gluten-free flour blend.

**Amaranth:** Amaranth has been cultivated as a seed for 8,000 years. Studies show that amaranth is an effective way to increase calcium, zinc, and iron which help strengthen your bones, improve circulation, optimize digestion, and boost immunity. Amaranth also lowers your appetite. Mostly, amaranth can be found in health food stores because it is not widely used yet, but demand for this fiber- and mineral-packed seed is growing. You can use amaranth as a filling breakfast cereal or as a creamy pudding or parfait.

**Annatto:** Annatto is an orange-red condiment and food coloring derived from the seeds of the achiote tree. It is often used to impart a yellow or orange color to foods, but is sometimes used for its flavor and aroma as well. Its scent is described as "slightly peppery with a hint of nutmeg" and its flavor as "slightly nutty, sweet, and peppery."

**Arborio Rice:** Arborio is a traditional Italian rice used often in dishes in which a creamy texture is desired. Risotto is a popular use for Arborio rice.

**Arrowroot:** Arrowroot starch/flour is a wonderful grain-free, paleo-friendly, gluten-free thickener and emulsifier. Use arrowroot starch one-for-one in place of cornstarch in your recipes. Added to baked goods, it creates a softer, lighter texture.

**Aspartame:** Aspartame is an artificial non-saccharide sweetener used as a sugar substitute in some foods and beverages.

**Autolyzed Yeast Extract:** Yeast extract is made from the same type of yeast used in baking or brewing beer. "Autolyzed" just means that this type of yeast is produced by broken-down yeast cells. Ensure the product is labeled "gluten-free" before using it.

**Baker's Yeast:** Baker's yeast is a common baking yeast that is used in breads to make them rise. It is naturally gluten-free.

**Basmati Rice:** Basmati is a fragrant, nutty-tasting variety of long, slender-grained rice which is traditionally from the Indian subcontinent.

**Benzoic Acid:** Benzoic acid is a compound widely used as a food preservative. It can be found in many plants or created in a laboratory.

**Beta-Carotene:** Beta-carotene is one of a group of red, orange, and yellow pigments called carotenoids. Beta-carotene and other carotenoids provide approximately 50 percent of the vitamin A needed in a healthy diet. Beta-carotene can be found in fruits, vegetables, and whole grains. It can also be made in a laboratory.

**BHT:** BHT (butylated hydroxytoluene) is a lab-made chemical that is added to foods as a preservative.

**Brown Sugar:** Brown sugar is a sugar product with a distinctive brown color due to the presence of molasses. It is either an unrefined or partially refined soft sugar consisting of sugar crystals with some residual molasses content (which is labeled as "natural brown sugar"), or it is produced by the addition of molasses to refined white sugar (which is labeled as "commercial brown sugar").

**Buckwheat:** Despite the word "wheat" in its name, buckwheat is a naturally gluten-free food related to the rhubarb plant. It's a versatile seed that can be steamed and eaten in place of rice. Alternatively, the whole seeds can be ground into a fine flour. Buckwheat has high levels of fiber and is a great source of protein. While most baking recipes will suggest using buckwheat as part of a flour blend with other ingredients like rice flour or almond flour, there are lots of recipes for pancakes that use 100 percent buckwheat flour. Or, try roasting the whole buckwheat groats and using them as an add-in for whole-grain granola.

**Calcium:** Calcium, the most abundant mineral in the body, is found in some foods, added to others, available as a dietary supplement, and is present in some medicines (such as antacids). It is an essential part of bones and teeth.

**Calrose Rice:** Grown in California, Calrose rice is the most popular type of rice in the United States and the Pacific. After cooking, Calrose rice grains hold flavor well, are soft and stick together, making it good for use in sushi.

**Canola Oil:** Canola is a crop with plants from three to five feet tall that produce pods from which seeds are harvested and crushed to create canola oil and meal. Canola seeds contain about 45 percent oil.

**Caramel Coloring:** This is the most used food coloring in the world. Made by heating carbohydrates, caramel coloring can be derived from wheat, but if it is, it will be listed on the packaging as "caramel color from wheat." If the label reads "caramel color," it is gluten-free.

**Carboxymethyl Cellulose:** Carboxymethyl cellulose (CMC), also known as "cellulose gum," is used as a thickener and emulsifier in food products.

**Carob Bean Gum:** Carob bean gum, also known as locust bean gum, is a thickening and gelling agent used in food products. It is extracted from the seeds of a carob tree.

**Carrageenan:** Carrageenan is an additive used to thicken, emulsify, and preserve foods and drinks. It's a natural ingredient that comes from red seaweed (also called Irish moss). You'll often find this ingredient in nut milks, meat products, and yogurt.

**Cassava Root and Flour:** Cassava is naturally gluten-free. The most commonly consumed part of cassava is the root, which is very versatile. It can be eaten whole, grated, or ground into flour to make bread and crackers.

**Chestnut:** Chestnuts contain very little fat—mostly unsaturated—and no gluten. They are the only "nuts" that contain vitamin C, with about 40mg per 100g of raw product. That is approximately 65 percent of the US recommended daily intake.

**Chickpea Flour:** The chickpea is a legume. Its different varieties are variously known as gram, garbanzo bean, or the Egyptian pea. They are high in protein and fiber.

**Coconut:** Coconut is naturally gluten-free and packed with nutrients. You can buy coconut as an oil, butter, flour, sugar, and flakes. In gluten-free baking, coconut flour is used most often in blends of other flours. The flour is made from dried, defatted coconut meat and is packed with fiber but low in carbohydrates. Coconut flour gives baked goods a rich texture and adds natural sweetness, which allows you to cut down on the amount of sugar in recipes. Coconut milk can be used in soups, stews, curries, beverages, and baked goods.

**Corn:** Corn is naturally gluten-free and can be used as a gluten-free substitute in many forms. Cornstarch can be used as a thickening agent in gravies or sauces. Corn flour can be used as a breading alternative and as a combination with other flours in baked goods. "Masa" is used in many Mexican dishes and is sometimes called "maize." And, of course, corn on the cob can be enjoyed with melted butter!

**Corn Gluten:** Corn gluten meal (CGM) is a gluten-free byproduct of corn ("maize") processing that has historically been used as animal feed. The expression "corn gluten" is colloquial jargon that describes corn proteins that are neither gliadin nor glutenin. Only wheat, barley, and rye contain true gluten, which is formed by the interaction of gliadin and glutenin proteins.

**Corn Syrup:** Corn syrup is a food syrup made from the starch of corn ("maize") and contains varying amounts of maltose and higher oligosaccharides, depending on the grade. Corn syrup, also known as glucose syrup to confectioners, is used in foods to soften texture, add volume, prevent crystallization of sugar, and enhance flavor.

**Cottonseed:** Cottonseed, the seed of the cotton plant, is important commercially for its oil and other products. Cottonseed oil is used in salad and cooking oils and, after hydrogenation, in shortenings and margarine. The cake, or meal, remaining after the oil is extracted is used in poultry and livestock feeds.

**Cream of Tartar:** Cream of Tartar is a white, crystalline, acidic compound obtained as a byproduct of wine fermentation and is used chiefly in baking powder.

**Dal:** Dal is a term used in Indian cooking to describe split peas or lentils. The term is also used to describe soups made from these products.

**Dasheen Flour:** A variety of taro root (also known as taro root flour), dasheen is a starchy edible tuber that can be used as a potato. However, raw dasheen is toxic, so it must be cooked. Boiling the tuber rids it of toxic calcium oxalate. This tuber is cream-colored to white and resembles a water chestnut. It has a mild, nutty flavor when cooked.

**Dextrose:** Dextrose is a simple sugar that is made from corn and is therefore gluten-free. Dextrose is commonly found in corn syrup and is used as a sweetener in processed foods and baked goods. Even if it is listed as "wheat dextrose," it is also gluten-free because it is highly processed which removes the gluten.

**Disodium Phosphate:** Disodium phosphate is a food additive. Phosphates like disodium phosphate are derived from the element phosphorus. Disodium phosphate is used as an emulsifier as well as to enhance cooking performance. It's used in packaged foods, including macaroni and pastas. You can also find it in meat products, some cheeses, canned sauces, Jell-O, evaporated milk, and some chocolate.

**Distilled Vinegar:** Distilled vinegar is used in salad dressings and marinades. In the United States, most distilled vinegars are made from corn, grapes, apples, or rice, all of which are gluten-free. Even if a distilled vinegar is made from wheat (usually outside of the USA), it is considered gluten-free since the process of distilling removes the gluten. Many non-distilled vinegars (such as "malt vinegar" which is fermented—not distilled—from wheat, barley, and/or rye) are **not** gluten-free, but the label will always tell you what ingredients were used in making the vinegar.

**Enriched Rice:** Enriched rice is white rice that has been coated with nutrients, such as iron, niacin, thiamin, and folic acid, which are lost when the rice is initially processed. Despite replacing some of the vitamins and protein, enriched rice is not as nutritious as whole grain brown rice.

**Ethyl Maltol:** Ethyl maltol is an organic compound that is a common flavorant in some confectioneries. It is white and solid with a sweet smell that can be described as caramelized sugar and cooked fruit.

**Fava Bean Flour:** Fava bean flour is naturally gluten-free. It has a distinctive flavor and is most often used in combination with garbanzo bean flour for gluten-free baking. Fava bean flour is perfect for all kinds of baking including breads, pizza, cakes, and cookies.

**Flaxseed Flour:** Flax is a naturally gluten-free food. Flaxseed flour, also called ground flaxseed, offers some benefits over whole flaxseed. Whole flax passes through your system undigested, causing us to miss out on its health benefits. Flax is full of fiber, which helps to relieve constipation, and the omega-3 fatty acids in flax reduce cholesterol and provide protection against heart disease. You can even replace some of the flour or all of the eggs in a baking recipe by substituting ground flaxseed.

**Fumaric Acid:** Fumaric acid is a common food additive included in many processed foods to keep them stable and add tartness. The substance is more sour than citric acid, another common food additive. Fumaric acid occurs naturally in fumaria, bolete mushrooms, lichen, and Iceland moss. As an additive, fumaric acid is produced synthetically, mainly from the malic acid in apples.

**Garbanzo Beans:** Garbanzo beans (also known as chickpeas) are naturally gluten-free. Flour made from this delicious bean lends a sweet, rich flavor to baked goods. It is also a wonderful ingredient for gluten-free baking. Garbanzo beans are loaded with protein and dietary fiber and are a good source of iron.

**Gelatin:** Gelatin was first used in Medieval Britain to create elaborate desserts and to make certain glues and adhesives. Now, it is mainly used as a colorless and tasteless protein in food, cosmetics, and medicine. In foods, this gluten-free additive is used not only as a dessert component, but also as a thickener. It is made from extracting the collagen from various animal parts.

**Glucose Syrup:** Glucose is made mostly from corn in the US, while Europe often uses wheat to make glucose syrup. Either type is considered safe for people with celiac disease since gluten is removed in the processing. Glucose syrup is used to enhance the volume and flavor of foods. It also prevents sugar from crystallizing, so the candy industry uses it a lot. Since glucose circulates in the bodies of animals as blood sugar, it is best to eat it in moderation.

**Glutinous Rice:** Sticky rice goes by many names—waxy rice, sweet rice, and pearl rice among them—but "glutinous" in its name is a bit confusing. Does glutinous rice actually contain gluten? The answer is no. Glutinous rice is gluten-free. The misleading name simply comes from the fact that glutinous rice gets glue-like and sticky when cooked.

**Gram Flour:** Gram flour is a naturally gluten-free legume flour made from a variety of ground chickpeas. It is often used to make Indian dishes.

**Guar Gum:** Guar gum is made from a seed native to tropical Asia and is used as a thickener in gluten-free recipes. Guar gum is good for cold foods such as ice cream or pastry fillings. It's a wonderful ingredient in gluten-free baking as well, since it provides the gluten-free dough with more elasticity.

**Hominy:** Hominy is made from whole corn kernels that have been soaked in a lye or lime solution to soften the tough outer hulls. It is gluten-free and typically used to make grits, but can also be used as a thickener for stew, to make tortillas or tamales, or as a dish all its own.

**Indian Rice Grass:** A wild grass first used by Native Americans thousands of years ago, Indian rice grass has a very versatile seed. Historic uses included: eating the raw seeds to relieve stomach ache, colic, and aching bones, and eating them cooked as dumplings. The seeds were added to soups and ground into flour and meal for cakes and bread. While they are rarely used as raw seeds anymore, this grass makes a terrific gluten-free flour.

**Instant Rice:** Instant rice is rice that has been precooked. Some types are microwave-ready, while others are dehydrated so that they cook more rapidly. Regular rice requires eighteen to thirty minutes to cook while instant rice needs one to seven minutes. Because it has already been cooked, you can simply microwave it or re-hydrate it with hot water. Be sure to check that gluten-containing flavorings haven't been added.

**Inverted Sugar Syrup:** Inverted sugar syrup, also known as invert syrup, is an edible mixture of two simple sugars (glucose and fructose) that is made by heating table sugar (sucrose) with water.

**Karaya Gum:** Karaya gum (also known as gum karaya or Indian gum tragacanth) is used as a thickener and emulsifier in food products. It is a vegetable gum created from the trees of the *Sterculia* genus.

**Kasha:** Kasha is organic buckwheat groats that have been hulled and roasted. It is 100 percent whole grain and makes a wonderfully flavorful hot cereal or delicious side dish.

**Lactic Acid:** Lactic acid is primarily found in soured milk products, such as yogurt, kefir, and cottage cheese. It is also used as a food preservative, curing agent, and flavoring agent.

**Lactose:** Lactose is a sugar present in milk and is gluten-free. It is a by-product of the dairy industry and is produced from whey. Lactose has a slightly sweet flavor, so it is a popular filler to bulk up baked goods. It also prevents caking of dry ingredients.

**Lecithin:** Lecithin is an essential fat that is found in many foods, such as soybeans, egg yolks, and in some supplements, as it contains an essential nutrient called choline. It is used in foods as an emulsifier to help ingredients stick together (think of flowing chocolate). Although lecithin is a fat, it is typically added in very small amounts, so the total fat content of any food should not be influenced by the presence of lecithin.

**Lentils:** Lentils are naturally gluten-free legumes that work well in place of noodles in soups and stews. They're rich in fiber and protein, making them a healthy meat substitute for vegetarians and vegans. Lentils are also packed with folate, iron, phosphorus, and potassium.

**Malic Acid:** Malic acid is a naturally occurring acid made by all living organisms. It contributes to the sour taste of fruits and is also used as a food additive to give candies a sour flavor.

**Maltodextrin:** Maltodextrin can be made from a variety of starches like potato, rice, corn, or wheat. In the United States, it is usually made from corn. Regardless, the starch is so highly processed that maltodextrin made from wheat is still gluten-free.

**Maltol:** Maltol is a naturally occurring compound extracted from the bark of larch trees and pine needles. It is used as a flavor enhancer in foods.

**Maltose:** Maltose is a sugar produced in the breaking down of starches and is therefore gluten-free.

**Mannitol:** Mannitol is a type of sugar alcohol used as a sweetener. Because it is poorly absorbed by the body, it is a good sweetener for diabetics. It can also be used as a medication to treat glaucoma and elevated intracranial pressure.

**Methylcellulose:** Methylcellulose is derived from cellulose, a common compound found in plants. It is used as a thickener and emulsifier in food products.

**Millet:** Millet is a naturally gluten-free grain that can be used as a whole grain (to replace rice, for example) or ground into a flour to be used for baking. It is a cereal crop that has been grown in India and Africa for hundreds of years, but only recently became popular in the United States. It is rich in minerals and protein, with 3g of fiber and 4g of protein per ¼ cup. Bake with it, try it out as a breakfast porridge, or try it as a replacement for corn-based polenta.

**Modified Corn Starch:** The FDA's Code of Federal Regulations spells out what can be used to modify corn starch, as well as other starches, and none of the allowed substances contain gluten. Modified corn starch sometimes appears on a label as "modified food starch." In that case, it is still gluten-free.

**Modified Tapioca Starch:** Modified tapioca starch is derived from tapioca and it is gluten-free. It is used in foods as a thickener and stabilizer. In baking, it can help improve the appearance and texture of products.

**Monosodium Glutamate:** Monosodium Glutamate, or MSG, is made by fermenting starches and sugars including corn starch, beet sugar, sugar cane, and tapioca starch.

**Nutritional Yeast:** Nutritional yeast is simply deactivated yeast. It has a nutty, cheesy, and creamy taste to it, making it a great ingredient for dairy-free cheese and butter products.

**Papain:** Papain is an enzyme extracted from the raw fruit of the papaya plant. These enzymes break proteins down into smaller fragments. It is a popular ingredient in meat tenderizer.

**Peanut Flour:** Peanut flour is made from crushed peanuts. The peanuts can be partly or fully defatted. Peanut flour, depending on the quantity of fat removed, is highly protein-dense, providing up to 52.2g of protein per 100g of peanuts.

**Pectin:** Pectin is a gelling agent found in jams and jellies. It is made from citrus peel or apples and is therefore gluten-free.

**Polysorbates:** Polysorbates are emulsifiers used in food production and pharmaceuticals.

**Potato Starch:** Potatoes and potato starch are naturally gluten-free. The starch is often used as a thickener for sauces, soups, and stews. Potato starch

tolerates higher temperatures than cornstarch when used as a thickener. It's a natural way to add moisture to many baked goods.

**Propylene Glycol:** Propylene glycol is a food additive that helps balance the amount of moisture in a food. It is also used as a solvent for food colors and flavors.

**Psyllium:** Psyllium fiber is made from the husk or outer shell of the psyllium plant's seeds. It provides a good source of natural fiber.

**Quinoa:** Quinoa is a naturally gluten-free superfood that contains all nine essential amino acids. Technically, it's a seed, but it is eaten like a grain. It comes in a variety of different colors like red, white, and black. Although quinoa has been consumed for thousands of years in South America, it's only recently that this protein-rich food became popular in the United States. Use whole quinoa as a replacement for rice and quinoa flour in baked goods.

**Red Rice:** Red rice is a variety of rice that is colored red by its anthocyanin content. It is usually eaten unhulled or partially hulled and has a red husk, rather than the more common brown husk. Red rice has a nutty flavor. Compared to polished rice, it has the highest nutritional value of rice eaten with the germ intact.

**Rice:** Rice is a naturally gluten-free grain and comes in many varieties. Rice flour (also rice powder) is made from finely-milled rice. Rice flour is a particularly good substitute for wheat flour. Rice flour is also used as a thickening agent in recipes that are refrigerated or frozen, since it inhibits liquid separation.

**Rice Bran:** The outer layer of the rice grain (bran) and the oil made from the bran are sometimes used for medicine. Rice bran oil is popular as a "healthy oil" in Asia, particularly in India. Be careful not to confuse rice bran with other forms of bran such as oat and wheat bran

**Sago:** Sago is a gluten-free starch taken from the center of sago palm stems. Sago has similarities to tapioca, including its look, taste, and feel. You can substitute tapioca for sago in many recipes. You can also use sago in the preparation of desserts and some breads. Sago is also sometimes used to make the Asian drink known as bubble tea.

**Sesame Seeds:** Sesame seeds are tiny, flat, oval seeds with a nutty taste and a delicate crunch. They come in a host of different colors depending on the variety, including white, yellow, black, and red. Not only are sesame seeds an excellent source of copper and a very good source of manganese, they are also a good source of calcium, magnesium, iron, phosphorus, vitamin B1, zinc, molybdenum, selenium, and dietary fiber.

**Sodium Benzoate:** Sodium benzoate is used as a food preservative, mostly in acidic products. It occurs naturally in fruits, vegetables, seafood, and dairy products.

**Sodium Metabisulfite:** Sodium metabisulfite (or sodium metabisulphite) is used as a preservative and antioxidant in food.

**Sodium Nitrate:** Sodium nitrate is used to preserve color and shelf life in processed meats. It is gluten-free but can be hard on people with sensitive stomachs.

**Sodium Sulfite:** Sodium sulfite (or sodium sulphite) is used as a preservative in food. Most commonly, it is found in dried fruit and preserved meat.

**Sorbitol:** Sorbitol is a sugar alcohol that the human body metabolizes slowly. Very similar to mannitol, it is usually created from corn syrup but can also be created from fruits like apples, pears, peaches, and prunes.

**Sorghum:** Sorghum is a naturally gluten-free grain that is used for many purposes in the gluten-free food world. The whole grain is ground into a soft flour that can be used for gluten-free baking. The flour has a smooth texture which makes it a perfect substitute in baked goods. Brewers often malt the sorghum grains and then use them to make naturally gluten-free beer. You can also use whole-grain sorghum as a replacement for rice. Steam the sorghum grain first, then top it with your favorite stir-fry ingredients to pack a nutritious punch. Every ¼ cup of sorghum flour is packed with 3g of fiber and 4g of protein.

**Soy:** Soy is a species of legume native to East Asia, widely grown for its edible bean, which has numerous uses. Soy foods are good sources of protein, and many are also good sources of fiber, calcium, potassium, magnesium, copper, and manganese.

**Spices:** Only 100 percent pure spices are gluten-free. Companies that use wheat flour to bulk up their spices exist, although they are few and far between. Thankfully, United States and Canadian labeling laws require these companies to disclose if wheat is used as a bulking agent. It is also prudent to look for gluten in the form of flour or dried soy sauce flakes in any premade spice mixes.

**Stearic Acid:** Stearic acid is used as a food additive, surfactant, and softening agent. It is obtained from fats and oils.

**Sucralose:** Sucralose is an artificial, non-caloric sugar substitute, making it an ideal sugar substitute for diabetics. When sold as a sweetener, it is often mixed with maltodextrin or dextrose. It is highly heat-stable, so it works well in baking.

**Sucrose:** Sucrose is another name for table sugar and is the most commonly found form of sugar. Sucrose is made from sugar cane and is gluten-free.

**Sunflower Seeds:** Sweet, nutty sunflower seeds are an excellent source of essential fatty acids, vitamins, and minerals. Besides being eaten as popular snacks, they are also used in the kitchen to prepare a variety of recipes.

**Sweet Rice Flour:** Sweet rice flour has some thickening properties, but it is better used in gluten-free flour mixes for baked goods. Sweet rice flour is ground from short-grain glutinous rice, also known as "sticky rice." Don't worry, though! The fact that it's called "glutinous rice" does not mean that it contains gluten.

**Tapioca Flour:** Tapioca flour helps to bind recipe ingredients and improves the texture of baked goods. It's slightly sweet and very starchy, so you only need a little bit of it in baked goods. You'll want to combine it with other gluten-free flours like brown rice or quinoa flour. Tapioca helps add crispness to crusts and chewiness to baked goods. It is an extremely smooth flour, which makes it a great thickener in sauces, pies, and soups and as a replacement for cornstarch.

**Taro Root:** Taro root is gluten-free and a good alternative carbohydrate to potato. Taro can be used in a similar way to a potato, but provides better nutritional value and a much lower glycemic index. Taro contains about three times more fiber and 30 percent less fat than potatoes. The low glycemic index of taro means that the blood sugar levels don't rise rapidly, making it a suitable food for diabetics and individuals with blood disorders.

**Tartaric Acid:** Tartaric acid is most commonly used to mix with sodium bicarbonate to create baking powder. It occurs naturally in many fruits and has a distinct sour taste.

**Tartrazine:** Tartrazine is a synthetic yellow dye primarily used as food coloring.

**Teff:** Teff is the smallest grain in the world. This African superfood is a great source of dietary fiber, protein, iron, amino acids, vitamin C, and calcium. It can be ground into flour to make an excellent gluten-free flour alternative and can be used to make pie crusts, cookies, breads, and an assortment of other baked goods. Teff can also be eaten whole, steamed, boiled, or baked as a side dish or a main course. Teff benefits blood sugar management, weight control, and colon health.

**Titanium Dioxide:** Titanium dioxide is a naturally occurring compound used as a food coloring.

**Tofu:** Plain tofu contains three ingredients: soybeans, water, and a curdling agent. As all of these ingredients are gluten-free, plain, unprepared tofu typically does not contain gluten. However, some varieties of flavored tofu are not gluten-free.

**Vanilla Bean:** Vanilla bean is grown from orchids in the genus "Vanilla" and is one of the world's most popular aromas and flavors.

**Vanilla Extract:** Vanilla extract is a solution made from crushed vanilla pods and ethanol. It is a very popular ingredient in Western desserts, especially baked goods.

**Wheat Starch (Only When Labeled Gluten-Free):**

Although wheat starch is made from wheat, **some** wheat starch is processed so that the proteins, including gluten, are taken out of the final product. This means it passes the Food and Drug Administration (FDA) regulations as being gluten-free (when the final product has 20 parts per million or less of gluten). The label also has to say that the wheat has been processed to allow this food to meet the FDA requirements for gluten-free foods. It is important to note that wheat starch is only safe for a person with celiac disease if the product is labeled "gluten-free," so be sure to read the labels thoroughly!

**Whey Protein:** Whey is the liquid that is left over after milk has been curdled and strained to make cheeses and yogurts. Whey is then dehydrated into a powder. It is the primary ingredient in most protein powders and is sold as a nutritional supplement to promote muscle growth and repair. Whey protein is found in a variety of flavors and added to liquid for ingestion. If you buy whey protein powder, be sure the mix doesn't contain "glutamine peptides," which are hydrolyzed wheat protein. Although the hydrolyzing process may remove most of the gluten, it is best if a celiac does not ingest it unless the mix has been tested to be gluten-free.

**White Rice Flour:** White rice flour is 100 percent stone ground from premium white rice. It is wonderful for gluten-free baking, as it results in light and fluffy cakes, pie crusts, and breads. It is also great for thickening sauces, gravies, and soups.

**Xanthan Gum:** Xanthan Gum is made from a microorganism called *Xanthomonas Campestris* and works best in baking and hot food preparations. It is a powerful thickening agent and is also used to prevent ingredients from separating. It is a crucial ingredient in most gluten-free baking. In gluten-free doughs, xanthan gum makes products more elastic and thick and gives baked products a better rise.

**Xylitol:** Xylitol is a sugar alcohol used as a sugar substitute. It does not affect blood sugar levels very much, making it a suitable alternative sweetener for diabetics.

**Yam:** Yams are a common name for sweet potatoes in the United States even though they are completely unrelated to each other. The yam is native to Africa and Asia. Yams are starchier and drier than sweet potatoes.

**Yuca:** Also known as cassava (and not to be confused with yucca), yuca is a dense, starchy food that is rich in carbohydrates. It's a good source of fiber, folate, vitamin C, and potassium. Like other starchy vegetables, it can be served fried, boiled, grilled, or mashed. When dried to a powder, it is known as tapioca.









