



Lexington-Fayette County Health Department

School Health
650 Newtown Pike
Lexington, KY 40508-1197
(859) 288-2314
(859) 288-2313 Fax

PARENT PACKET – CELIAC DISEASE / GLUTEN INTOLERANCE

Dear Parent/Guardian:

You have informed us that your student has Celiac Disease or gluten intolerance. Enclosed are the forms, which need to be completed by the Parent/Guardian and returned to the School Nurse. This information will help us determine how best to help your student during the school day.

Please send a current picture of your student in order for the student to be easily identified. This information will be distributed to appropriate school personnel on a need-to-know basis and may include bus drivers, substitute teachers, cafeteria staff, and others who work with your student daily.

To help your student, please let us know of any changes in your student's medical condition or emergency daytime phone numbers.

The following need to be returned to the School Nurse.

- Celiac / Gluten Intolerance Healthcare Plan
- Food Services Modification Form

We are looking forward to a great year with your student! Please call the Health Department's School Health Program at 288-2314 if you have any questions.

CELIAC DISEASE / GLUTEN INTOLERANCE HEALTHCARE PLAN

Student's Name: _____ **DOB:** ____ / ____ / ____

School: _____ Teacher: _____ Grade: _____

Parent/Guardian(s) Name(s): _____

Address/Zip Code: _____

Physician: _____ Phone #: _____

Hospital of Choice: _____

Parent/Guardian 1: – Home: _____ Work: _____ Cell: _____

Parent/Guardian 2: – Home: _____ Work: _____ Cell: _____

Place
Student's
Picture
Here

Or call Emergency Contact if unable to reach Parent/Guardian:

Name: _____ Phone: _____ Relation: _____

*** PARENT/GUARDIAN: PLEASE INDICATE IF YOUR STUDENT HAS ANY ADDITIONAL FOOD ALLERGIES or other FOOD INTOLERANCES: No Yes**
If "YES" please complete an Allergy Packet and return to your School Nurse.

Please check known symptoms your student has had to Gluten exposure:

- | | | |
|---|---|---|
| <input type="checkbox"/> Diarrhea | <input type="checkbox"/> Vomiting | <input type="checkbox"/> Stomach ache, abdominal cramps, gas |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Seizures | <input type="checkbox"/> Irritability or other behavior changes |
| <input type="checkbox"/> Bone pain | <input type="checkbox"/> Mouth sores | <input type="checkbox"/> Numbness or tingling in legs |
| <input type="checkbox"/> Low energy | <input type="checkbox"/> Weakness | <input type="checkbox"/> Hair loss, lack of hair growth |
| <input type="checkbox"/> Muscle cramps | <input type="checkbox"/> Protruding abdomen | <input type="checkbox"/> Weight loss, not gaining weight |
| <input type="checkbox"/> Loss of appetite | <input type="checkbox"/> Nausea | <input type="checkbox"/> Missed menstrual cycle |

Date of student's diagnosis of Celiac Disease / Gluten Intolerance? ____ / ____ / ____

Date of student's last Gluten-induced episode? ____ / ____ / ____

Will you be sending lunch and snack to school with your student each day? Yes No

Does your student know unsafe foods and ingredients to avoid? Yes No

Do you see a healthcare provider for management of Celiac Disease / Gluten Intolerance? Yes No
 Healthcare provider's name: _____ Phone: _____

Do you see a Dietician/Nutritionist for management of Celiac Disease / Gluten Intolerance? Yes No
 Dietician/Nutritionist name: _____ Phone: _____

Can the school send a letter home notifying parents of students in the classroom about your student's Celiac disease to decrease the chances of Gluten-containing foods being brought to school? Yes No

How do you manage your student's Celiac Disease / Gluten Intolerance at home? (Diet restrictions, etc.)

Additional comments: _____

FOOD SERVICE MODIFICATIONS EATING AND FEEDING EVALUATION

This form must be completed and signed by a Physician if your student requires a dietary restriction. (i.e. no peanut butter, no strawberries, etc.) OR a food substitute (i.e. allergic to cow's milk – substitute soy milk).

This also pertains to other dietary accommodations (i.e. pureed foods, thickened liquid, etc.)

This form is good for one school year and must be completed and signed by student's Physician to reverse a previous accommodation (i.e. "Student no longer restricted on strawberries – Please lift restriction," "Student no longer requires pureed foods – Please lift restriction" etc.)

PART A			
Name of Student: _____		DATE OF BIRTH: ____ / ____ / ____	
Name of School: _____	Grade: _____	Classroom: _____	
Does student have a Disability/Special Need? If Yes, describe the major life activities affected.		<input type="checkbox"/> Yes	<input type="checkbox"/> No
Does student have special nutritional or feeding needs? If Yes, complete Part B of this form and have it signed by student's Physician.		<input type="checkbox"/> Yes	<input type="checkbox"/> No
<i>IF STUDENT DOES NOT REQUIRE SPECIAL MEALS, PARENT/GUARDIAN CAN SIGN AT THE BOTTOM OF THIS FORM AND RETURN THE FORM TO THE SCHOOL'S FOOD SERVICE.</i>			
PART B			
List any dietary restrictions or special diet:			
List any allergies or food intolerances to avoid:			
List foods to be substituted:			
List foods that need the following change in texture. If all foods need to be prepared in this manner, indicate "All." Cut up or chopped into bite-size pieces: Finely ground: Pureed:			
List any special equipment or utensils that are needed:			
Indicate any other comments about student's eating or feeding patterns:			
Parent/Guardian's Signature: _____		Date: ____ / ____ / ____	
Physician's Signature: _____		Date: ____ / ____ / ____	

Reviewed by: _____ RN Date: _____

Celiac Sprue Association

www.csaceliacs.org

Dear Parent,

To say the least, you have had to make some adjustments in your lifestyle since discovering that your child has celiac disease. You have learned diligence in finding all the places that wheat, barley, rye and oats* (WBRO) can hide in food, medications, personal-care products, art supplies, and sizing and materials in clothing. You have become your child's greatest health advocate and now it is time for you to help your child to be safe at school. The Celiac Sprue Association (CSA) has produced a set of materials designed to help the various school professionals that will work with your child. The following are a few suggestions on how to get the most out of these materials and encourage a positive learning experience for your child at school.

1. First, it is helpful to realize that, just as you may have struggled to learn all the parameters of this new way of living, the school staff may struggle as well, and will occasionally miss the mark. Your patience and helpful attitude will go a long way toward making the transition a successful one for all involved. Open, honest, non-confrontational communication is the key to creating a positive environment for your child and the adults who will work with him or her.
2. Review each piece of material before giving it to the respective school staff member. It may be helpful to highlight or note those things that are especially true for your child, as well as those things that do not pertain to your child. This will assist the learning process for each of them.
3. Take time to sit down and visit with your child's Teacher, Principal, School Nurse, Counselor, and cafeteria workers. It might be advantageous to have the Principal arrange this meeting so everyone can meet at the same time, forming a team that will work together to ensure your child's safety. Most people in education are there because of their love for children, so in general, this team will want to do what they can to provide a positive educational experience for your child. As you are aware, knowledge is power and you hold the keys to the knowledge needed in this situation - please share them with those who will be serving your child. When awkward situations arise, humor can often be used to ease the tension.

During the team meeting you will want to discuss the following:

- Basics about Celiac Disease and/or Dermatitis Herpetiformis.
- Other health concerns your child may have.
- Your child's specific symptoms.
- Bathroom requirements.
- Snacks - provide a Gluten-free snack list.
- Classroom activities that might pose special problems.
- Any playground concerns.
- Cafeteria concerns.
- Contact information to include phone numbers for you, your Pediatrician and your Dietitian.
- Arrange to provide a "just in case" box with snacks for those times when treats are brought in that are not safe for your child.

Be sure to point out that the school is responsible to:

- Review your child's health record.
- Include your child in school activities with appropriate modifications.
- Identify a core team to work with you and your child to establish a safety plan.
- Ensure that all staff who will interact with your child are aware of his or her special needs.
- Coordinate with the School Nurse to ensure that he/she is prepared for any emergencies. (If Latex is a concern, make sure that the Nurse is aware of this.)

- Prepare to handle a reaction. Share with the staff what past reactions have been like and how they were handled.
- Work with the district, if needed, to ensure that the cafeteria will be able to provide food options that are safe for your child.
- Prepare to handle challenges that could present themselves on class field trips.
- Follow all laws and regulations regarding the sharing of your child's medical information.
- Take seriously any harassment and/or threats that may occur against your child because of his/her condition.

Inform them that your child knows that he or she is responsible to:

- Not trade food with others.
 - Not eat anything with unknown ingredients or which contain WBRO.
 - Notify an adult immediately if he or she eats or touches something that may contain WBRO.
 - Be proactive in the care and management of symptoms based on his or her developmental ability.
4. Remember, your approach to this disease and to the meeting will set the tone for the school year. Be positive and upbeat and you'll find that the school will follow suit. Your child will take cues from you as to how to interact with others regarding this disease. Your example of positive, cooperative communication will help him or her become a strong advocate for self while being polite, courteous and understanding with others.
5. Additional information and support is available through the Celiac Sprue Association. As the largest non-profit organization dedicated to helping people with celiac disease and dermatitis herpetiformis, CSA offers individualized support and a variety of educational materials.

Your attitude of understanding and care will go a long way toward helping those who deal with your child at school learn how best to meet his or her needs. Remember, this is new for them, as well. Be patient and soon the necessary changes will become a normal part of the school routine.

* Reprinted with permission from Celiac Sprue Association.

GLUTEN-FREE SNACK, CANDY & SCHOOL PRODUCT LIST

SNACKS

- ◆ Lays STAXX (All flavors)
- ◆ Ruffles Regular potato chips
- ◆ Mission Tortilla chips
- ◆ Orville Redenbacher's popcorn
- ◆ Act II popcorn (except extreme butter)
- ◆ Jiffy Pop Popcorn
- ◆ Crunch 'n Munch
- ◆ Jell-O Brand gelatin and pudding snacks
- ◆ Del Monte Pudding cups
- ◆ French's Potato Sticks
- ◆ Frigo/Kraft/Sargento cheese sticks
- ◆ Ore-Ida French Fries
- ◆ Old Wisconsin Beef sticks
- ◆ Hormel Pepperoni
- ◆ (GLUTEN FREE versions of cookies, pretzels, crackers, cupcakes)

FRUIT SNACKS

- ◆ Kroger's, Nabisco & General Mills Fruit Snacks
- ◆ Farley's Brand Gummy Bears
- ◆ Favorite Brand Fruit Gummies
- ◆ Fruit to Go (SunRype)
- ◆ Trolli Gummi Candies—all
- ◆ Fruit by the Foot
- ◆ Sunkist Fruit Rolls
- ◆ RaislNs
- ◆ Welch's Fruit Snacks

JUICE BOXES

- ◆ Mott's, Minute Maid, Del Monte, Juicy Juice — all
- ◆ Capri Sun
- ◆ Hawaiian Punch
- ◆ KoolAid — all
- ◆ Northland 100% Juice
- ◆ Welches juices — all
- ◆ Libby's — all

DRINKS

- ◆ Coke, Sprite, Minute Maid
- ◆ Pepsi, Mountain Dew, Sierra Mist
- ◆ 7-Up, A&W Root Beer, Country Time
- ◆ Big K brand soft drinks
- ◆ Snapple — all
- ◆ Crystal Lite
- ◆ Swiss Miss Hot Chocolate

ICE CREAM NOVELTIES

- ◆ Flintstones Pushups
- ◆ Dole Fruit N Juice Bars
- ◆ Edy's/Dreyers Fruit Bars
- ◆ Koolaid Freezer pops
- ◆ Nestle's Popsicles
- ◆ Starburst Fruit Juice Bars
- ◆ Minute Maid Fruit juice Bar
- ◆ Good Humor Popsicles
- ◆ PhillySwirl Frozen Stix
- ◆ Fla-Vor-Ice

ICE CREAM

- ◆ (Vanilla, Chocolate & Chocolate Chip are usually safe. Avoid obvious ingredients.)
- ◆ Baskin Robbins
- ◆ Edy's Grand
- ◆ Edy's Homemade
- ◆ Ben&Jerry's
- ◆ Blue Bell
- ◆ Blue Bunny
- ◆ TCBY
- ◆ Cool Whip
- ◆ Dairy Queen
- ◆ Dreyers

CHOCOLATE CANDY

- ◆ Hershey's Kisses & Hugs
- ◆ Hershey's milk chocolate bars (except Crispy or Cookie)
- ◆ Hershey's Nuggets (except Cookie)
- ◆ M&M's (except Crispy)
- ◆ Nestle Butterfinger BB's
- ◆ Nestle Chunky
- ◆ Raisinets
- ◆ Reese's Peanut Butter cups
- ◆ 3 Musketeer's
- ◆ Baby Ruth
- ◆ Butterfinger
- ◆ Snickers
- ◆ Clark Bars
- ◆ Dove
- ◆ York Peppermint Patties

CHEWY CANDY

- ◆ Flavor Rolls—all
- ◆ Jellybelly jellybeans
- ◆ Tootsie Rolls—all
- ◆ Starburst Fruit Chews
- ◆ Jolly Rancher Fruit Chews
- ◆ Double Bubble — all
- ◆ Wrigley's chewing gum — all
- ◆ Trident gum — all
- ◆ Skittles
- ◆ Milk Duds
- ◆ Airheads
- ◆ Big League Chewing Gum
- ◆ Bubble Yum — all
- ◆ Chicklets
- ◆ Dentyne Gum — all
- ◆ Haribo Gummies
- ◆ Sharie's Gummies
- ◆ Trolli Gummies
- ◆ Gold Medal Cotton Candy

HARD CANDY & SUCKERS

- ◆ Charms—all
- ◆ Farley's hard candies
- ◆ SweetTarts
- ◆ Spree
- ◆ BitOHoney
- ◆ Spangler DumDum Pops
- ◆ Tootsie Pops
- ◆ Extreme Pops
- ◆ LifeSaver's (all)
- ◆ Jolly Rancher hard candy & Lollipops
- ◆ Topps Ring Pops
- ◆ Pez
- ◆ Smarties
- ◆ Wonka: Bottlecaps, Gobstoppers, Mix Ups, Pixy Stix,
- ◆ Shocktarts, Tart 'N Tiny, Fun Dip (Lik-M-Aid), Laffy Taffy,
- ◆ Nerds, Runts, Tangy Taffy, Nips.
- ◆ Haviland (Necco) Candy Stix

SCHOOL PRODUCTS

CRAYOLA (800-CRAYOLA)

ALL Crayola products are GF EXCEPT Crayola Dough. This includes: Markers; Washable markers; 3D markers; Chalk; Oil pastels; Mess Free Color Wonder; Jumping Colors; Model Magic; Crayons (regular, washable and metallic); Colored Pencils; Glue Paint; Silly Putty

ELMER

ALL Elmer brand products are GF EXCEPT Finger Paints which contain wheat. This includes: Tempera paints; Paint pens; All glue; Mucilage; All purpose Glue Stick; Glitter; Glitter Shakers

PALMER PAINT (800-521-1383)

All Palmer Paints are gluten free.

ROSS PRODUCTS (888-435-6377)

ALL Ross products are GF EXCEPT for the Finger Paints. This includes: Ross White Glue; Glue Sticks; School Glue

LAKESHORE Learning Materials

(800-428-4414) ink pads contain wheat protein.

CENTER ENTERPRISES

(800-542-2214) would not guarantee whether or not their ink pads contain wheat.

PRANG Washable Paint

(800-824-9430) and NASCO Washable Tempera Paints (800-558-9595) are both gluten free.

MAGIC

Crayons (regular, washable and metallic); Colored Pencils; Glue Paint; Silly Putty
NOTE: Washable Finger Paints contain Dextrins.

ROLES IN THE MANAGEMENT OF STUDENTS WITH CELIAC DISEASE / GLUTEN INTOLERANCE

PARENT/GUARDIAN'S RESPONSIBILITIES

- Notify the school of the student's Celiac Disease / Gluten Intolerance prior to the start of the school year OR as soon as possible after a new diagnosis
- Fill out and return the packet sent in the mail or sent home
- Provide a list of products and/or ingredients to avoid
- Work with the school team to develop a plan that accommodates the student's needs throughout the school including in the classroom, in the cafeteria, in after-care programs, during school-sponsored activities, and on the school bus
- Attach a current photograph of your student to the forms sent to you
- Educate the student in the self-management of their Celiac Disease / Gluten Intolerance including:
 - * Safe and unsafe products
 - * Strategies for avoiding exposure to Gluten
 - * Symptoms of reactions to Gluten exposure
 - * How and when to tell an adult they may be having a Gluten-tolerance related problem
 - * How to read food labels when applicable (age appropriate)
- Review policies/procedures with the school staff, the student's physician, and the student (if age appropriate) after a reaction has occurred.
- Provide emergency contact information and notify school immediately if information changes!
- Provide the School Nurse with a Physician's Statement if student no longer has Celiac Disease / Gluten Intolerance.
- Leave a bag of "Safe Snacks" in your student's classroom so there is always something your student can choose from during an unplanned special event

SCHOOL'S RESPONSIBILITY

- Be knowledgeable about and follow applicable federal laws including ADA, IDEA, Section 504, and FERPA.
- Review the health records submitted by Parent/Guardian(s) and Physicians.
- Include students with Celiac Disease / Gluten Intolerance in school activities; students should not be excluded from school activities solely based on their Gluten intolerance.
- If it will not negatively impact their academic progress, consider clustering students with Celiac Disease / Gluten Intolerance in the same classroom to promote peer support and avoidance of Gluten.
- Assure that all staff who interact with the student on a regular basis work with other school staff to eliminate the use of Gluten in the Gluten intolerant student's meal, educational tools, arts and crafts projects, or incentives.
- Review policies/prevention plan with the core team members, Parents/Guardians, student (age appropriate), and Physician after a reaction has occurred.
- Work with the district transportation administrator to assure that school bus driver training includes symptom awareness and what to do if a reaction occurs.
- Take threats or harassment against an Gluten intolerant student seriously
- Discuss field trips with the family and students with Gluten intolerance to decide appropriate strategies for managing the intolerance.

RESPONSIBILITIES OF THE CLASSROOM TEACHER

- Participate in in-service training offered by the School Nurse that addresses the student with Celiac Disease / Gluten Intolerance.
- Be sure volunteers, student teachers, aides, specialists and substitute teachers are informed of the student's Celiac Disease / Gluten Intolerance and necessary safeguards.
- Leave information in an organized, prominent, and accessible format for substitute teachers
- Educate classmates to avoid endangering, isolating, stigmatizing, or harassing students with Celiac Disease / Gluten Intolerance; be aware how the student with Celiac Disease / Gluten Intolerance is being treated; enforce school rules about bullying and threats.
- Inform parents of any school events where food will be served if a student has Celiac Disease / Gluten Intolerance
- Never question or hesitate to act if a student reports signs of a reaction to Gluten.
- Use stickers, pencils, or other Gluten-free non-food items as rewards instead of food to decrease the risk of reactions.

CLASSROOM TEACHER - FIELD TRIPS

- Notify the School Nurse two weeks prior to a scheduled field trip and include date, time and location.
- Ensure that a functioning cell phone or other communication device is taken on field trip.
- Review plans for field trips – avoid high-risk places.
- The student's safety or attendance must not be conditioned on the Parent/Guardian's presence. Parent/Guardian must complete a background check prior to field trip in compliance with Fayette County Public School Policy.
- Consider ways to wash hands before and after eating and cross-contamination in cases of Celiac Disease / Gluten Intolerance.

CAFETERIA RESPONSIBILITIES

- Read all food labels and recheck routinely for potential Gluten.
- Train all food service staff and their substitutes to read product food labels and recognize Gluten-containing ingredients.
- Review and follow sound food handling practices to avoid cross contamination with potential Gluten exposure.
- Be aware of which students have Celiac Disease / Gluten Intolerance.

SCHOOL NURSE RESPONSIBILITIES

- Prior to entry into school or immediately after diagnosis ensure Celiac Disease / Gluten Intolerance packet received from Parent/Guardian.
- As soon as possible, notify all staff who come in contact with the student with Celiac Disease / Gluten Intolerance - including Principal, Teachers, Specialists, Food Service personnel, Aids, PE Teacher, Bus Driver, etc.
- Place the health condition in Infinite Campus

STUDENT'S RESPONSIBILITIES

- Should not trade food with others if has Celiac Disease / Gluten Intolerance.
- Should not eat anything with unknown ingredients or known to contain any Gluten if has Celiac Disease / Gluten Intolerance.
- Should be proactive in the care and management of their Celiac Disease / Gluten Intolerance and reactions based on their developmental level.
- Should notify an adult immediately if they eat something they believe may contain Gluten.
- Wash hands before and after eating if has Celiac Disease / Gluten Intolerance.
- Learn to recognize symptoms of a reaction to Gluten exposure.

It is important that children take on more responsibility for their Celiac Disease / Gluten Intolerance as they grow older and are developmentally ready. Consider teaching them to:

- 1. Communicate the level of severity of their Gluten intolerance.**
- 2. Communicate symptoms as they appear.**
- 3. Read labels as applicable.**