Celiac Support Group
Boston Children’s Hospital
300 Longwood Ave, Boston, MA 02115
Phone 617-355-2127
celiacsupportgroup@childrens.harvard.edu

Celiac Support Group
Boston Children’s Hospital

School Packet

2009
Fall 2008

Dear Celiac Support Group Parents,

We hope this educational packet will provide you with information and tools to help make you and your child’s school experience happy and safe. As parents of children with celiac disease, we must educate the educators.

This packet is just one of the tools you bring to your working relationship with individual teachers and the school system. Remember that your child is one of many, each of whom brings his or her own special needs and concerns to the classroom.

Try to help your child’s teachers in any way that you can. Work to build a positive relationship, while also educating and advocating for new systems to minimize your child’s risk of exposure to gluten.

Some material in the packet can be photocopied and distributed to persons whom you think would benefit from the information. Other material is simply for your reference.

Fortunately, the state Department of Education (DOE) is behind this effort as well. The DOE has distributed guidelines to help school personnel in managing life-threatening allergies and food sensitivities. This packet will help you understand those guidelines, how they can help a student with celiac disease, and how some school districts have implemented the guidelines.

If you have questions or concerns that are not addressed in this packet, feel free to contact the Celiac Support Group at Boston Children’s Hospital for additional support.

Good Luck,

Tara Taft & Susan Cummings
Co-Presidents
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**Material in pocket**

Pamphlet for MA school personnel – “Managing Celiac Disease in the School Setting”

Doctor’s letter to School Personnel

List of Gluten Free Snack Options
1) Preparing Yourself and the School for the Entrance of Your Celiac Child

Food is everywhere in the school system from preschool and day-care through middle school, high school, and of course in college when they are "almost" on their own. Regardless of your child’s age and level of school, it is important that you maintain a positive relationship with the school as you discuss options for keeping your child safe from gluten exposure. Remember, you are your child’s best advocate and a successful advocate has a positive working relationship that will foster change.

The following ideas have been compiled to assist parents as they begin to prepare a school or day-care center for the entrance of their celiac child. This list is not all inclusive. Every school and celiac child is unique. Please use only ideas that help you in setting up a plan for your child’s school.

**General**

- **Get a letter** from your pediatrician or gastroenterologist (GI) confirming your child’s medical condition, and if necessary, outlining the specifics needed in school to maintain your child’s well being. (Be sure the letter states that celiac disease is a life long disease, so you will not need a new letter each year.)

- **Prepare to set aside time** for multiple meetings before and after school starts. Learn who you need to talk to at the school one year before your child will enter. If there are community events at the school, attend them with your child so that you can both become familiar with the school. Start your gluten-free food planning meetings the spring before or at least the summer before your child will begin attending the school. Some schools are closed in the summer, so make sure they are open if you are going to wait until then.

- **Always make appointments** with school personnel (e.g., school nurse, principal, food service director, teachers, specials – art, speech, etc.). Be prepared. Bring a photo of your child if they’ve never met her or him. Show gratitude, show appreciation, and offer to pitch in and help.

- **Create a written plan** for your child together with essential school personnel. Include procedures for all situations in which food is involved that is specific and detailed. (See section in the folder for a description and examples of a 504 plan.)

- **Review the plan** as needed, but at least twice a year for adjustments.
• **Keep meetings** regarding food issues **separate** from meetings regarding academic performance as much as possible.

• **Avoid discussing your child’s health issues at school with teachers and parents in front of him** as much as possible.

• **Write thank you notes.**

• **Follow up and stay on top** of those who aren’t cooperating and document. Remember it is your child’s health that you are protecting.

• **Review the Massachusetts Department of Education guidelines for “Managing Life Threatening Allergies in the Schools”;** know what is being recommended to schools and know that you are not alone). See [www.doe.mass.edu](http://www.doe.mass.edu).

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**Preschool, Day-care, and Elementary School**

As you prepare your plan for the coming year, **inquire about the following:**

**The Classroom**

• Classroom size and teacher/child ratio.
• Has this school or teacher supervised children with food issues before?
• If yes, what kinds of plans were put into place?
• Is the teacher(s) comfortable with your child’s medical condition and with making the changes necessary for your child to be safe, welcomed and included?
• Is there a full-time nurse?
• Are there other children with food issues in the class?

**Snacks**

• Are snacks served and who provides them?
• Is there a list of snack foods and drinks traditionally provided by the school?
• Are containers used to store snacks thoroughly cleaned and are they gluten free?
• Are there safe hand and face washing policies in place?
• Are tables cleaned after snacks are eaten?
• Are children allowed to share food?

**Lunch and the Cafeteria**

• How and when are tables and chairs cleaned after food is served?
• Where is lunch served?
• If your child’s lunch needs to be heated, what adult will safely do so?
• Are there any gluten-free foods offered (see middle and high school student cafeteria section)?

Birthday Celebrations

• How are birthdays traditionally handled?
• Can a frozen cupcake be kept in the teacher’s freezer?
• Can a bag of candy or special snack be kept in the teacher’s desk?
• Can parents be encouraged to send in non-food items (e.g. stickers or pencils) to celebrate birthdays?

Special Activities and Other Celebrations

• Which holidays are observed in school and which ones involve food?
• Are parents allowed to bring in food treats unannounced?
• If food is a must, encourage fruit and cheese instead of donuts and cake.
• Ask that the teacher contact you ahead of time so that you know what will be served.

Curriculum

• Is there a sensory table? Instead of barley, flour, and pasta, suggest substituting rice and beans.
• Do they cook in school? If so, when and what? Suggest using a flour free recipe and/or using a gluten-free flour mixture (you can provide).
• Does counting or estimating numbers involve food (e.g., m & m’s, cereal)?
• Is food used in science projects?
• Are there non-food substitutions that can be made?
• Review all curriculum plans in detail for any areas where changes need to be made.

Art

• Are there food materials used in art?
• Is food used in crafts (e.g., pasta necklaces, cereal collages). Suggest using gluten-free versions or avoiding the use of food altogether.
• Is play dough used? Commercially made play dough has wheat flour as a main ingredient. You can make your own “play dough” by using rice flour and corn starch (give them the recipe).
• Are stickers or envelopes used? The adhesive in many stickers and envelopes contains gluten. Suggest using self-sticking crafts to avoid any risk.
• Is pudding used to paint with?
• Is papier mache used? Most paper mache recipes contain wheat flour. Rice flour or any gluten-free flour mix can be substituted.

Field Trips

• How many field trips are taken?
• How are the students transported and supervised?
• Is there food of any kind involved?

Other

• Ask school personnel if and how they will educate children in the class about food issues.
• Ask school personnel if and how they will educate parents of children in the class about food issues.

• Research recipes that work ahead of time for school celebrations. Most common needs will be candy, cookies, cakes, ethnic celebration foods, and traditional holiday foods.

• Prepare to volunteer for gluten-free food needs that the teacher or school may have.

• Consider giving the teachers a list of gluten-free snacks which your child can eat.

• Ask the school if it will distribute a letter explaining individual student food issues and describing the school plan for snacks, birthdays, and school celebrations. The letter should not name children specifically, rather state that there are children with food issues, so as not to single out your child and draw attention that may make your child feel uncomfortable now or when they older.

Congratulations yourself on taking great care of your very special celiac child.

Middle and High School

Middle School and High School is often the time when students become most concerned with assimilation. For this reason, spending the time to determine what, if any, foods provided in the cafeteria are gluten-free may be very important for your child’s emotional well being. Eating the ‘same’ foods at lunch as their peers often is especially important to the student with celiac disease. Some students may bring their own lunch from home, however, many middle and high school cafeterias will have an increased selection of foods and snack items and, hopefully, some of these options may be gluten-free.
While the use of food within the classroom may decrease because of fewer parties, it can still be present in the curriculum. The use of food as “rewards” may also continue. Bake sales or other foods for purchase for fund-raising events can exist. Unlike in elementary school, your child may now be hesitant to have a parent approach the teacher or the school. The middle or high school student may decide to handle this issue on their own, or simply bear with it and eat nothing.

Some things a parent can do at this stage:

- **Contact the cafeteria** - Contact the head of food service during the spring prior to your child's entry into the school and explain the dietary restrictions. Request the opportunity to read the ingredients on food labels and the ingredients used in the cafeteria. Contact the companies yourself to determine the gluten-free status of questionable ingredients. Learn about the preparation techniques of potentially safe items, (i.e. are the French fries baked or fried? If fried, is the oil contaminated? Are the French fries coated with any unsafe seasonings or flavorings?) Read the labels of anything you think your child might consume (a note of caution, some hamburger patties contain oats or other fillers).

  Check to see if your child can obtain permission to purchase 'snack' items as part of the price of their regular lunch and make sure that staff are aware of this arrangement. For example, yogurt, chips and fruit offered as a "snack" may be good additions to their meal. Likewise, if your child can only safely purchase a portion of the lunch offered, make sure that staff are aware of this and that the child does not have to explain this in front of their friends.

- **Research school trips** - School trips are often a part of the middle/high school curriculum. Start early to research the places the school may take the students to eat on these events. Provide portable foods to supplement the celiac student's diet, if necessary. If you are lucky, you may be able to encourage the selection of restaurant choices that are able to provide a gluten-free menu selection (however, if they go for pizza, the options will be slim at best). Contact the restaurants yourself and supply the student with the gluten-free options in advance, if possible.

- **Establish open lines of communication** - Although your student may want their independence and feel that you no longer have a role, establish open lines of communication with the teachers and the administration. Gently remind them to avoid singling out your child so that the student will be less embarrassed. Work as a team and don't forget common courtesy when arrangements are made to accommodate your child’s diet.
Congratulations on taking great care of your very special celiac adolescent.

College and Letting Go

The college search from start to finish is a daunting process. It is best not to address celiac disease issues until college acceptances arrive in the mailbox. The time to deal with this issue, and all that living away from home will entail, begins as these acceptances arrive. The dietary needs of the celiac child shouldn’t be the focus in deciding which school to choose, but there are some things to bear in mind when doing the college search.

Parents should keep an eye out for certain things when looking at potential schools on those campus tours. Notes on each school will be helpful when your child prepares their short list after determining all their other criteria. Keep in mind the larger the student body, the more dining service options, the greater the chances for variety in dormitory living, health services, etc. The following are a few things to consider when looking at schools.

- Access to a kitchen will be very helpful. Do the dormitories, especially freshman dormitory options, have suites with kitchenettes; or do the regular dormitories have kitchenettes on each floor perhaps at the end of the hall or near the lounge area?
- Are microwaves and refrigerators allowed in dorm rooms? This is essential!
- Does the campus have little food markets and do they stock gluten free items?
- Do the cafeterias on campus offer a variety of food options?
- What is the quality of the salad bars? There will be times when your child can only find his/her meal at the salad bar!
- Can your child walk to a large grocery store or health food store safely from the campus?
- Is apartment living plentiful for upper classmen? Is it a popular option? Is it on or off campus? Is it safe if you have an off campus apartment?

Once your child has decided on their school and the deposit is in the mail, it is time to do what you do best - call the school and ask to be connected to the head of the dining services department. Be prepared to explain the disease completely. The following are some areas to address when talking to the dining services.

- Is there a registered dietician affiliated with the dining services department or school that might help address your child’s needs?
- Do they service (feed) other celiac students? If so, how many are there and how do they meet their needs?
• Do they provide education to their staff about celiac disease, including the servers, so they understand if the student asks for something such as a clean pan for a stir-fried option?
• Will they provide a vendor list of everything the dining service offers? The summer will provide time to research which items are safe. It also allows time to educate the school and show how the current practices limit options for your child. For example, it is difficult if all of the chicken offered is coated with a modified food starch that isn’t gluten free or if all the Asian foods are mixed with a soy sauce that contains gluten. It is amazing the changes that can result when you show them how little is offered that is gluten free from dining services.

  When one school in the Midwest discovered that what they provided was so limited, they offered to purchase Amy’s frozen dinners, gluten free snacks, cereals and other gluten free items weekly and deduct it from the child’s meal plan. They also delivered it to the child.

• Will they provide each cafeteria’s menus in advance to your child? This enables your child to know where to go on campus for food. Menus are always planned in advance and repeated in cycles, so this shouldn’t be a problem.
• Will they provide freezer and refrigerator storage space for extra food in a cafeteria close to their dormitory room?
• Set up an appointment for you and your child with the head of food services for the day of arrival on campus. (Better yet, at a freshman orientation program.) This allows your child to meet the person with whom he/she will be in contact for their dietary needs over the next few years. Once they are on campus, they will have to be their own advocate and learn to work with the system and the system with them.

The next telephone call should be to the residential offices or housing department. Find out the living options for freshmen at the school. Offer to provide a physician’s letter describing celiac disease and the dietary limitations so that your child can be placed in a living situation that provides a kitchen/kitchenette near their dorm room. This will allow your child to have first preference when room assignments are made in the early summer. Inquire if hot plates, George Foreman grills and appliances of that nature that can be used in dorm rooms. Most schools say no, but it is worth a try and maybe getting an exception. A must for a dorm room is a refrigerator and microwave. Find out the allowed voltage and buy them. When roommate assignments arrive and the call is made to the prospective roommate, maybe they’ll opt to bring the TV and DVD player while your child offers to bring the microwave and refrigerator!

Research the school’s meal plans. A declining balance option plan (a fixed amount put aside for the meal plan, much like a debit card) is usually the best plan due to the limited gluten free food options provided in the dining services.
You can add money to these plans as necessary. Other options usually are ‘use it or loose it’!

Remember all schools have Offices of Disability Services and schools have to meet 504 criteria since this is a medical condition so make this call early, especially if the previous calls have hit roadblocks.

Remember, when shopping for the dorm room, that your child will need a place to store gluten free food in their rooms, and space is always tight in dorm rooms!! Bed risers, or concrete blocks that lift the bed to provide extra storage underneath, will help. They will need paper and plastic cups, plates, and utensils since they will probably eat in their room to supplement the dining hall food. (Disposable items helps keep dish washing to a minimum, but make sure they are microwavable!) Also a pot, colander and some cooking utensils will be helpful.

Alcohol exposure at college is generally expected, and most children turn 21 in college. They will need to know which alcohols are gluten free and which are not at a time when you feel it is appropriate to discuss this issue.

Remember, your child will get sick at school. They will have to educate the infirmary/health center staff about their celiac disease if they get sick enough to need care. New HIPPA laws make it hard for parents to talk to the infirmary staff. It only occurs with your child’s permission since they are over 18 years old!! Issues can come up that your child may want to keep private, for example birth control pills, antibiotic treatment for a sexually transmitted diseases, etc. Our children need to make sure all medicines that they are prescribed or that are purchased over the counter are gluten free. On a lighter note, send your child to college with over the counter, gluten free vitamins and commonly used medications for colds, head aches, fevers, indigestion, etc. It may save a late night call home asking you what to do when you are not able to help.

In closing, your child will need to advocate their needs to dietary services. Making sure meals are gluten free is their job now. It makes the college adjustment a little more difficult. They will have to plan more than their roommate about their meals. Care packages from home and from gluten free vendors are a must! But remember, you’ve taught them well. They will manage. You will probably get a few frustrated telephone calls, but it gets easier and college will be the experience you and your child wanted with a lot of fun thrown in!!!!!

**Congratulations** on taking great care of your very special celiac young adult.
2) **The Celiac Student AND the Massachusetts Department of Education Guidelines for “Managing Life Threatening Food Allergies in the Schools”**

The Massachusetts Department of Education (DOE) issued the Managing Life-Threatening Food Allergies in Schools guidelines in the Fall of 2002. These guidelines were presented to assist school districts and nonpublic schools to develop and implement policies and comprehensive protocols for the care of students with life-threatening allergic conditions. The report explains how food allergies are on the rise and because of their increasing prevalence and life-threatening nature, schools need to be prepared.

The celiac student is at risk when exposed to gluten. Although the celiac child will not have an anaphylactic life threatening reaction, for some children with celiac disease there may be an immediate reaction of vomiting if they ingest gluten. Independent of their outward reaction, ingestion of gluten for celiac children will damage the lining of their small intestines and severely compromise the celiac child’s health, growth and development.

The report suggests that schools should have risk reduction procedures in place. An aspect of these procedures includes ideas on minimizing the use of food in the schools wherever possible. Schools are encouraged to think of alternatives to using food in their curriculum, birthdays and special parties so as to minimize exposure and risks. Therefore, the guidelines that speak specifically to minimizing exposure to foods will directly benefit the student with celiac disease.

The full guidelines can be found on [www.doe.mass.edu](http://www.doe.mass.edu)

**Prevention:**
Prevention is the key to managing celiac disease. Guidelines taken directly from the manual (pg 16) which would be helpful to the student with celiac disease include:

**Classroom**
- Have all teachers, aides, volunteers, substitutes and students educated about the disease.
- For rewards, non-food items should be used instead of candy.
- For birthday parties, consider a once-a-month celebration with a non-food treat.
- Sharing or trading food in the class should be prohibited.
- Proper hand washing technique by adults and children should be taught and required before and after the handling/consumption of food.
o There should be an understanding that classroom project material containing the allergen not be used.
o Tables should be washed with soap and water in the morning if an event has been held in the classroom the night before.

**Food Services / Cafeteria**

Food service staff needs to be prepared to discuss menus, a la carte items; vending machines; recipes, food products and ingredients; food handling practices; cleaning and sanitation practices; and the responsibility of various staff

Cross contamination is the cooking or serving of different foods with the same utensils and surfaces. When preparing and serving food, it is critical to make sure that food preparation and serving utensils are not exposed to allergens and then used for another food. Food production surface areas should be cleaned before, during and after food preparation.

**Roles of Specific Individuals: (taken directly from the manual Appendix A pg. 26):**

**Student**

Take as much responsibility as possible for avoiding allergens.

Do not trade or share foods.

Wash hands before and after eating.

Promptly inform an adult as soon as accidental exposure occurs or symptoms appear.

Take more responsibility for your allergies as you get older.

Develop a relationships with the school nurse and/or another trusted adult in the school to assist in identifying issues related to the management of the allergy in the school.

**Parent of student**

Inform the school nurse of your child’s allergies prior to the opening of school.

Provide a list of foods and ingredients to avoid.
Establish prevention plan.

Help decide upon a safe eating area in the classroom and/or cafeteria.

Leave a bag of “safe snacks” in your child's classroom so there is always something your child can choose from during an unplanned special event.

Be willing to provide safe foods for special occasions e.g. bring in a treat for the entire class so that your child can participate.

Provide a non-perishable lunch to keep in school, in case our child forgets lunch one day.

Teach your child not to share snacks, lunches, or drinks.

Teach your child the importance of hand washing.

Teach your child to report any teasing, bullying and threats to an adult authority.

Teach your child to take as much responsibility as possible for his/her own safety. (e.g. read labels when able.)

**School administration (Principal, Health, Food Services Director)**

Support faculty, staff and parents in implementing all aspects of the LTA (Life Threatening Allergies) program.

Consider a risk reduction plan.

Provide training and education to faculty and staff e.g. foods, risk reduction.

Provide training to food service personnel.

Inform parent or guardian of any student experiencing a reaction.

Make sure a contingency plan is in place in case of a substitute teacher, nurse, or food service personnel.

**School nurse**

Prior to entry into school, develop a prevention plan for the student with parents and all staff that come in contact with the student.
Educate personnel as necessary.

Conduct in-service training and education for appropriate staff regarding risk reduction procedures.

Provide information about students and their photos (with consent of parent) to all staff on a need-to-know basis.

Introduce self to student and show him/her how to get to the nurse's office.

Meet with parents on a regular basis to discuss issues relating to plan implementation.

**Classroom Teacher / Specialist**

Be sure substitute teachers are aware of the student’s celiac disease.

Educate classmates to avoid endangering, isolating, stigmatizing or harassing students with food allergies. Be aware of how the student with the food allergies is being treated; enforce school rules about bullying and treats.

Work with the school nurse to educate parents about the presence of allergies in the class and enlist their help in keeping certain foods out of the classroom.

Inform parents of any school events where food will be served.

In the classroom, establish procedures to ensure that the student eats only what s/he brings from home.

Encourage parents/guardians to send in a box of “safe” snacks for their child.

Prohibit students from sharing or trading snacks.

Have parent/guardians provide a non-perishable safe lunch in case their child forgets lunch one day.

Avoid cross-contamination of foods by wiping down eating surfaces with soap and water before and after eating.

Reinforce hand-washing before and after eating.

Avoid use of foods for classroom activities (e.g. arts and crafts, counting, science projects, parties, holidays, and celebrations, cooking or other projects.)
Welcome parental involvement in organizing class parties and special events. Consider non-food treats.

Use stickers, pencils or other non-food items as rewards in stead of food.

**Food Services Staff**

Attend team meeting when planning for student.

Read all food labels and recheck routinely for potential food allergens.

Train food service staff and their substitutes to read product food labels and recognize food allergens.

Maintain contact information for manufacturers of food products.

Review and follow sound food handling practices to avoid cross contamination with potential food allergens.

Strictly follow cleaning and sanitation protocol to avoid cross-contamination.

Train Monitors

Enforce hand washing for all students.

Thoroughly clean all tables, chairs, and floors after each meal.

After receiving a doctor’s note, make appropriate substitutions or modifications for meals served to student with food allergies.

Provide advance copies of menu to parents/guardians and notification if menu is changed.
### 3) FOOD IN SCHOOL PROTOCOL

The following is a sample of how local public schools are managing the school environment to keep all children safe and to promote healthy eating habits. We have gathered information on the use of foods in schools by conducting interviews with nurse managers, by direct contact and by speaking with other policy makers. This research was conducted in March 2004.

#### Food area

<table>
<thead>
<tr>
<th>Schools</th>
<th>B-DAY PARTIES</th>
<th>HOLIDAY PARTIES</th>
<th>BAKE SALES</th>
<th>SCHOOL BUS ROUTES</th>
<th>SHARING OF FOOD</th>
<th>FOOD IN CURRICULUM</th>
<th>FOOD AS REWARDS</th>
<th>WRITTEN PROTOCOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>BELMONT</td>
<td>No food allowed</td>
<td>Food discouraged</td>
<td>Clearly labeled</td>
<td>Discouraged</td>
<td>Prohibited</td>
<td>Handled individually</td>
<td>Not allowed</td>
<td>Yes</td>
</tr>
<tr>
<td>LEXINGTON</td>
<td>No food allowed*</td>
<td>No food allowed*</td>
<td>After hours only</td>
<td>No food</td>
<td>No statement</td>
<td>Handled individually</td>
<td>Stress education &amp; prevention</td>
<td>Yes, being updated</td>
</tr>
<tr>
<td>N. ANDOVER</td>
<td>No food allowed*</td>
<td>No food allowed*</td>
<td>No statement</td>
<td>No food</td>
<td>“restricted”</td>
<td>Under review</td>
<td>Not allowed</td>
<td>Yes</td>
</tr>
<tr>
<td>NEWTON</td>
<td>No food allowed</td>
<td>No food allowed</td>
<td>Food must be labeled</td>
<td>No food</td>
<td>Prohibited</td>
<td>Not encouraged</td>
<td>Not allowed</td>
<td>Yes, draft</td>
</tr>
<tr>
<td>STOW</td>
<td>No food allowed</td>
<td>No food allowed</td>
<td>Not allowed</td>
<td>No food</td>
<td>Prohibited</td>
<td>Not used</td>
<td>Not allowed</td>
<td>Yes</td>
</tr>
<tr>
<td>AMESBURY</td>
<td>No food allowed</td>
<td>No food allowed</td>
<td>With special</td>
<td>No food</td>
<td>No statement</td>
<td>No food allowed</td>
<td>Not allowed</td>
<td>Yes, student handbook</td>
</tr>
</tbody>
</table>

**Amesbury:** Amesbury does not allow food in the curriculum. For special classroom events that include the consumption of food, permission must be granted first by the principal and then written consent is required form the parents to allow their child to participate. Auxiliary groups must follow the school’s handbook and individual principal discretion.

**Belmont:** Has written protocol, but is continuing to work on issues.

**Lexington:** Every classroom adapts its on policy for celebrations based on the age of the child. Their policy is being revised for better implementation. Attempting to eliminate dinners from school functions. Food free parties are a goal. Suggest donate books to the classroom in lieu of cupcakes.

**N. Andover:** Functions to be activity based. Food should be for nutrition not used as a reward.

They attempt to limit food donations by requesting that parents refrain from bringing in food unless they have been specifically designated to do so. Their health and food safety policy (2/03) is under review as a result of a new superintendent.

**Newton:** Eliminates the use of food for rewards and celebrations. Encourage the use of non-food items such as stickers, pencils. And designate a day of the month to recognize special events with non-food alternative such as reading a book or creating a sign. No food sales in elementary school stores. Prohibits the sharing or trading of food. Food is allowed on longer bus trips with supervision.

**Stow:** Protocol states that food products will not be used to support the curriculum. Food will not be used as a reward or incentive in the classroom. If there are any exceptions they must be approved by the building principal. All participating students with food issues must be notified in advance. A food policy is currently being reviewed by the Nashoba Regional School District. This will supercede the existing protocol.
4) Explanation of the 504 Plan and Examples of What Some Celiac Students Have Listed in their 504 Plan

Section 504 is part of the Rehabilitation Act of 1973, and applies to all institutions receiving federal financial assistance, such as public schools. Under this law, public schools must provide a free appropriate public education and not discriminate against disabled students. This law acknowledges that the disability may not require special education services but a plan is needed to ensure the student receives an appropriate education accommodating the disability within the classroom. This law must accommodate a special diet.

To request a 504 Plan, parents need to speak with the 504 Coordinator in their school and submit a note from their child’s doctor. The note should clearly state the disease, symptoms, and necessary precautions / accommodations. Without a doctor’s note, the school can deny your request. A meeting will then be arranged for the plan to be developed.

The document for the plan generally includes an explanation of the student’s disability and lists specific accommodations that will need to be made. For the celiac student, accommodations should cover the general areas of: health department, classroom, art room, and food services.

Is the 504 Plan for my child?
The 504 plan is not designed specifically for celiac students and therefore isn’t a perfect fit. This may or may not be a useful resource for families. Each family will need to evaluate the pros and cons for their situation to determine if they want to pursue a 504 plan. One celiac support group member, Marie Nogueria-Stamas says, “I felt it was appropriate to place my child on a 504 Plan not to have her labeled as disabled but to ensure that she would be able to participate in as many activities as possible, with the correct accommodations.” She goes on to say, “Knowledge is power, by having the plan in place the lines of communication are better between parents and teachers. The teacher has a written and legal document to consult with when making lesson plans. Also the teacher knows as parents we are there to help in any way possible. Our goal is to have school be a fun, safe, positive, healthy learning experience for our child.”

Examples of what some celiac students have listed in their 504 Plan:

Health Department
- Faculty and staff training regarding the plan
- Presentation to class on hand washing procedures
- Health assessment should any sign or symptoms occur indicating possible accidental or known exposure to gluten.
• Insuring communication systems are in place for persons who need to know i.e. substitute teachers

Classroom:
• Parent and teacher will work together to monitor classroom events that may include the use of food.
• An alternative to using food treats for student’s birthdays will be selected.
• Class activities using envelopes will be minimized and child reminded not to lick any envelope/stickers in class.
• Custodian will complete daily cleaning of the classroom.
• Student should be allowed bathroom privileges when necessary
• Student cannot use any of the following materials for classroom projects: play dough, paper mache, fruit loops and cheerios and other gluten containing food, pasta, flour, paste, envelope and stamp adhesives. Parents will provide a list of alternative materials if the class plans to use any of these materials.
• The teacher will communicate with parents about upcoming projects which may require alternative foods or materials.

Art Room:
• Food will not be distributed in the art classroom.
• Products commonly used in the art room will be reviewed to determine that they are gluten free. Any changes in art products will be communicated prior to instituting the change. (e.g. paper mache and play dough)

Food Services:
• Student will be encouraged to keep her lunch in her lunch box while eating.
• Student will be encouraged to wipe the section of the table she is eating on prior to eating.
• Necessary cleaning procedures for the cafeteria tables and microwave will be followed.
• Parent and Food Services will work together to arrange procedures when student is ordering school lunch or bringing food from home that will require heating in the cafeteria. (e.g. warming in the oven on a separate foiled cookie sheet).
• Tables and hands will be washed before and after eating.

Field Trips:
• Teachers will communicate to parent if food will be provided as part of field trip.
• Parent will determine whether food is gluten free and/or provide student with a safe alternative.
Gluten Free Snack Ideas

Here are some examples of generic snacks for school. We have omitted any brand names as ingredients change often. **You can choose the specific brands that your child enjoys once you have confirmed the gluten free status with the manufacturer.**

- Fruit (fresh, frozen, canned)
- Vegetables (fresh, frozen, canned)
- Chips (potato and corn and soy)
- Rice cakes
- Popcorn
- Nachos, Taquitos, quesadillas, tacos, tamales (made from corn)
- Nuts
- Cheese
- String Cheese
- Cottage Cheese
- Cream Cheese
- Rice Crackers
- Eggs
- Tuna
- Fruit rolls
- Seeds (i.e. Sunflower, Pumpkin)
- Peanut Butter
- Hummus
- Popsicles (100% FRUIT JUICE)
- Raisins and other dried fruit
- Marshmallows
- Chocolate
- Jello
- Individual packaged pudding
- Custards
- Yogurt

**Beverages:**
- Milk
- 100% Juice – No Added Flavorings
- Hot Chocolate Made With Pure Cocoa Butter
- Most Carbonated Drinks
- Tea/Coffee

Prepared by Boston Children’s Hospital – Celiac Support Group 2008
To Whom It May Concern:

This letter is to inform you that you have a student with celiac disease. Celiac disease is an autoimmune disorder that damages the small intestine and interferes with proper absorption of nutrients. People who suffer from celiac disease cannot tolerate a protein, gluten, found in wheat, barley, rye and possibly oats.

Gluten is found throughout the Western diet and is widely used in processed foods and oral medications. In addition, there are some hidden sources of gluten both in food and in unusual items such as art supplies and postage stamps. Maintaining a gluten-free diet can be challenging but not impossible when appropriate supports are in place.

If the student with celiac disease inadvertently ingests gluten, his or her parents should be notified. There are a variety of symptoms that children may display when exposed to gluten. A physical exam by a doctor or school nurse may be needed. Some children develop gastrointestinal (GI) upset manifested by vomiting, diarrhea, gas, bloating or constipation. Other children display more subtle symptoms such as inability to concentrate, restlessness, irritability, or sleepiness. Symptoms can come on suddenly or occur a few days later. Some children may not display any overt symptoms, but exposure to gluten will have damaging effects on their small intestine. Reinforcing good hand-washing techniques can help prevent inadvertent ingestion of gluten.

Celiac disease is not an allergy. Exposure to gluten does not cause anaphylactic reactions. Therefore, an Epi-pen is not needed. The student does not need to take medications for celiac disease.

To best prepare for events in the classroom, it is advisable to meet with the parents of the celiac child early, preferably before the school year starts. Parents are your best resource for obtaining clarity about what the celiac student can and cannot eat. Establish a consistent communication plan with your student’s parents throughout the year. A developed clear plan with regard to school projects, field trips, parties and meals in the cafeteria is needed. You can support your student by limiting or removing food used as part of the curriculum or in classroom celebrations. If food needs to be used, consider using gluten-free alternatives. It is also important to maintain the student’s privacy and not single them out based on this diet restriction.

Since there are a number of persons in the school that will have an impact on the student, it is helpful that all persons are informed of the child’s condition and that information be shared. The brochure “Managing Celiac Disease in the School Setting” being distributed by The Massachusetts Department of Education (DOE) can provide assistance. The brochure contains general risk reduction actions as well as specific actions that can be taken by the nurse, classroom teacher, art teacher, and food services manager and staff.

The Celiac Support Group at Boston Children’s Hospital can also provide additional information and updated lists of acceptable gluten-free substitutes and recipes. Other helpful websites are: http://www.celiac.org or www.celiac.com. If you should have any further questions, please do not hesitate to contact us.

Sincerely,

Alan M. Leichtner, MD
Medical Director