

# Celiac Disease: New patient guide to care



**Boston  
Children's  
Hospital**

Celiac Disease  
Program

# Contents

Documentation.....	1
Virtual “New to Celiac Disease” parent meet-up.....	1
Schedule your family to attend the “Gluten-Free Education” class....	2
Follow-up appointments to schedule .....	3
Screening family members for celiac disease .....	4
Sign-Up for the MyChildrens Patient Portal.....	5
Research collaboration .....	5

Welcome to the Celiac Disease Program at Boston Children’s Hospital. This document outlines the pathway of care for a child with celiac disease and the many support services offered through the hospital.

Sign Up for Information! The Celiac Disease Program offers a variety of re-sources for patients and families. These resources include information on ed-ucation and community programming, research opportunities, and our Celiac Kids Connection Support Group. To sign up to receive information about these opportunities, please visit: <https://redcap.link/1u95413v>

## Documentation

Your child’s diagnosis may have been made using a combination of blood work and an endoscopy. These records are available through the patient portal. Please print and keep copies of these records for future evidence of the diagnosis. We will also provide you with a copy of a diagnosis letter.

## Virtual “New to Celiac Disease” parent meet-up

Every Thursday from 1 p.m. to 2 p.m. EST, our team hosts a live virtual meeting for families to learn about all of the resources available through Boston Chil-dren’s Celiac Disease Program and the Celiac Kids Connection Support Group. This is also a great time to ask any questions. Feel free to bring your lunch to this meet-up! Register at: <https://bostonchildrens.zoom.us/meeting/register/tJwqceGorDosGdbFlJDqtDfStAIYR0Q6hcM9>

# Schedule your family to attend the “Gluten-Free Education” class

This class is led by one of the dietitians from our Celiac Disease Program.

This 90-minute class addresses the gluten-free diet, reading food labels, safe, unsafe and questionable ingredients, and other important lessons. There will be lots of time to ask your questions! You are welcome to invite grandparents, babysitters and anyone else who cares for your child. Please call to schedule this visit within one week of receiving a diagnosis. Classes are held at the following times/locations: Please note, all classes are currently being held virtually:

- Boston (Main Hospital): first, third and fifth Thursday of the month, from 9 a.m. to 10:30 a.m. Please call 617-355-4677 to schedule.
  - Peabody: second Thursday of the month from 3:15 p.m. to 4:30 p.m. Please call 781-216-3400 to schedule.
  - Waltham: second Monday of the month from 3:00 p.m. to 4:30 p.m. Please call 781- 216-1800 to schedule.
- Following the “Celiac Disease: Getting Started” class, **please schedule an individual appointment** with one of our Celiac Disease Program dietitians. Please schedule this visit after having been on the gluten-free diet for at least two months. To schedule a dietitian visit, please contact the facility you would like to visit:
    - Boston (Main Hospital): 617-355-4677
    - Peabody: 781-216-3400
    - Waltham: 781-216-1800

- **Schedule a visit with our school specialist or social worker to discuss celiac disease accommodations in school.** There are several federal laws that public schools and those that receive federal funding are required to follow, including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. Most private schools also have a formal documentation plan process to manage the needs of a child with celiac disease. Our team can work with you and your child’s school to set up a plan to ensure a safe and inclusive school year. You can schedule this visit at the following link: <https://bostonchildrens.zoom.us/meeting/register/tJMqduuhqTsjEtf8Ss7gPbJ-p0ofwF0kOOVh>
- The **Celiac Kids Connection** is the patient and family support group for Boston Children’s Celiac Disease Program. The group provides a net-working community of support, education, and advocacy for families with children diagnosed with celiac disease. Annual dues are \$35, but financial assistance is available if needed. To join the group, please visit: <https://www.celiackidsconnection.org/>

## Follow-up appointments to schedule

Please note your date of diagnosis as all appointments are scheduled from this time. You can schedule all of these appointments any time following notification of a celiac diagnosis.

- Within one week of diagnosis – schedule “**Celiac Disease: Getting Started**” class with dietitian
- Within two weeks of diagnosis – schedule meeting to discuss “**Celiac at School Accommodations**”
- Within one month of diagnosis – schedule appointment for **celiac testing** for parents and siblings
- **Individual dietitian appointment** – please schedule this appointment for four to eight weeks after you have attended the gluten-free diet class.
- **Gastroenterologist follow-up visits** – please schedule appointments for two months, six months and 12 months from the date of diagnosis. After the first year, appointments are typically scheduled annually.

# Screening family members for celiac disease

Celiac disease has a genetic component, meaning that it runs in families. It's important that **first-degree family members are screened for celiac disease**. We recommend that you speak to your primary care physician for adult screening and pediatrician for sibling screening.

- Please make sure the following tests are ordered: **tissue transglutaminase (tTG-IgA)** and **total serum IgA**. Please note, you must be consuming gluten daily in order for these tests to be accurate.
- If your child's labs are positive, please call our Gastroenterology Program to schedule an appointment to review the results and discuss next steps.
- If your labs are positive, please contact an adult gastroenterologist to schedule an appointment to discuss the results. We work closely with several adult providers and can help connect you to a physician.
- If your child's labs are negative, but you still are concerned about celiac disease, please discuss additional testing options with your child's gastroenterologist.

# Sign-Up for the MyChildrens Patient Portal

The MyChildrens Patient Portal is the best method to communicate with your child's medical providers. Please send only brief, non-urgent messages through this system. To sign-up, please visit: <https://apps.childrenshospital.org/mychildrens>. Your child's medical record number is the password to log in.

## Research collaboration

Research helps us to better understand celiac disease, develop new treatments and diagnostic tests, and improve the quality of care that you receive, but we can't do it without you! We rely on strong partnerships with our patients and their families to participate in research initiatives locally in Boston and collaboratively across the United States and around the world. Occasionally, we may send you a survey to fill out, ask you to submit samples of blood, stool, or urine, or participate in clinical trials. We hope you will consider joining in with some of these projects.

Please contact [celiacresearch@childrens.harvard.edu](mailto:celiacresearch@childrens.harvard.edu) or sign up at <https://redcap.link/1u95413v> if you would like to volunteer to participate in research.

Please note that you and your child are not obligated to participate in research and your decision will not impact your child's clinical care.



Where the world comes for answers

**Boston Children's Hospital Celiac Disease Program**

300 Longwood Avenue, Fegan 5  
Boston, MA 02115

Other locations:

**Boston Children's at Peabody**

10 Centennial Drive  
Peabody, MA 01960

**Boston Children's at Waltham**

9 Hope Avenue  
Waltham, MA 02453

Phone: 617-355-6058