

WELCOME TO THE  
Congenital Diaphragmatic  
Hernia Program





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## About the program

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When your child has a congenital diaphragmatic hernia (CDH), their diaphragm does not fully develop, which allows abdominal organs to move into the chest, preventing normal lung development. In many cases, diaphragmatic hernias can be successfully treated in newborns, and the outlook for babies born with CDH is increasingly positive.

Children with CDH require follow-up care and treatment over time to minimize related health concerns, such as lung problems, breathing difficulties, gastrointestinal problems, and growth and development concerns. The Congenital Diaphragmatic Hernia Program (CDHP) at Boston Children's Hospital is dedicated to treating and managing long-term follow-up care for children born with this complex health concern.

### Our approach to CDH

Because every case of CDH is different, it's important to have an experienced team of clinicians on your side. In the CDH Program, pediatric surgeons and specialists in pulmonary medicine, gastroenterology, otolaryngology, cardiology, orthopedics, child development, nutrition and genetics work together to treat all aspects of your child's health. We treat more than 19 newborns with CDH each year, giving us the deep expertise necessary to care for these children.

When CDH is suspected prenatally, Boston Children's Maternal Fetal Care Center assists families through a coordinated program of care, including diagnosis and counseling, prenatal monitoring, treatment at delivery and postnatal care. We are also a center of excellence for extracorporeal membranous oxygenation (ECMO) and have published extensively on this approach. This advanced technology functions as a replacement for a critically ill child's lungs and is beneficial for babies with CDH.

Some babies come to our program when a diagnosis of CDH is made after birth. In addition, our team oversees an outpatient CDH clinic.

Established in 1989, the clinic is longest-running follow-up clinic of its kind in the world and monitors and treats the long-term health needs of CDH patients, from early childhood through young adulthood.

# Your visit

Our regular CDH clinic runs the second and fourth Monday of every month, excluding holidays.

During your visit, you and your child will see clinicians from multiple specialties including general surgery, pulmonology, nutrition, developmental medicine, nursing, and social work.

A typical individual visit with each physician can last 15 to 45 minutes, and you can expect to wait about 15 to 20 minutes between providers. This is so our team can gather to share information and go over clinical notes with each other before the next physician sees you.

Our program coordinator will schedule your child's chest x-ray prior to your visit and can coordinate any other necessary appointments or tests. Keep in mind that this can make for a long day at the hospital. Please note: We will try to coordinate visits with Cardiology on the same day of your visit, but this is subject to availability and advanced notice.

## CDH Program locations

### General Surgery

#### • Fegan 3

Check in here for your clinic visit

### Nuclear Medicine

#### • Main 2

For VQ scans and other tests

### Radiology

#### • Main 2

For chest and other x-rays

### Cardiology

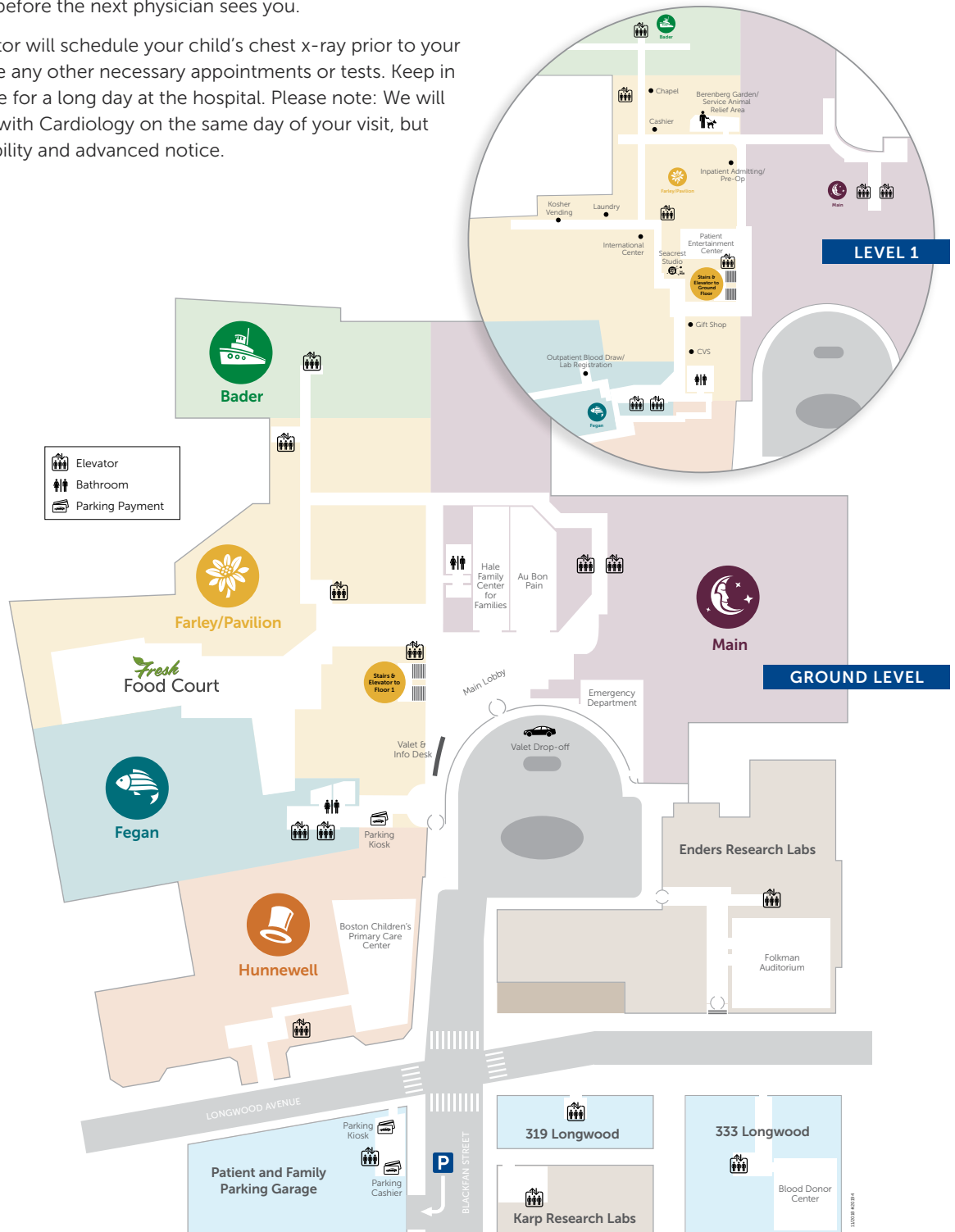
#### • Farley 2

For ECHO and cardiologist visits

### Pulmonology Lab

#### • Farley 4

For pulmonary function testing



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## Travel and accommodations

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### Getting to your appointment

Boston Children's is located at 300 Longwood Avenue, Boston, MA 02115

#### MBTA

The main campus of Boston Children's Hospital is easily accessible by public transportation. The Green D and E subway lines and certain commuter rail stops are closest to the hospital. A variety of bus lines (#8, #8A, #47, #60, #65, #CT2 and #CT3) run near the hospital as well.

#### PT-1

If your child qualifies for MassHealth insurance and you need help getting to Boston Children's for outpatient appointments, you may qualify for a PT-1. This service is available for curbside-to-curbside transportation and generally must be set up at least three days in advance of your outpatient appointment. Ask your social worker for more information.

#### Driving

Directions are available [bostonchildrens.org/directions](https://www.bostonchildrens.org/directions).

#### Parking

There is a parking garage located across the street from the hospital on Blackfan St. Parking can be validated for a reduced rate in the main lobby of the hospital. Valet services are available at the front entrance (free for handicap placard/plate families; extra cost for all other families). You can also choose to self-park in the garage.

The phone number for the parking office is 617-355-6251. The Hale Center for Families offers parking assistance for income-eligible families (inpatient families only).

#### Plane

The closest airport is Boston's Logan International Airport. Many families travel to and from the airport via taxi. Some hotels offer shuttle service as well.

#### Travel assistance

In some cases, insurance (most often state Medicaid) can assist with travel costs (transportation, lodging and meals). Check with your child's health insurance provider to see if they offer this.

Some children may qualify for free flights to and from Boston for medical care. Generally, you must qualify based on finances. You can find a list of organizations that provide these flights at [aircarealliance.org](https://www.aircarealliance.org).

Some children may qualify for discounted or charitable plane tickets on behalf of various major airlines. Information on the application process can be found at [mercymedical.org/request-assistance](https://www.mercymedical.org/request-assistance).

Some children and families may qualify for gas cards, commercial bus tickets or Amtrak tickets to and from Boston. Information on the application process can be found at [mercymedical.org/request-assistance](https://www.mercymedical.org/request-assistance).

### Patient and family accommodations

Accommodations in Boston can be very expensive and difficult to find. The best option for you will depend on your financial resources, the number of people traveling with you, your anticipated length of stay, and your own need for company vs. privacy. Whether you choose to stay in the hospital, hospital housing, a hotel or a furnished rental, keep in mind that advanced planning is strongly recommended.

#### The House at 21 Autumn St.

21 Autumn St., 5<sup>th</sup> Floor, Boston

#### Yawkey Family Inn

241 Kent St., Brookline  
617-919-3450

[childrenshospital.org/familyhousing](https://www.childrenshospital.org/familyhousing)

- \$30 a night
- Private rooms with shared bathrooms for Boston Children's families
- Walking distance to hospital
- Communal kitchen, laundry facilities, internet access
- Parking available in Boston Children's garage for a discounted rate with ticket validation
- Reservations may be made up to three months in advance
- A limited number of one-bedroom apartments are available for \$50 a night

#### Hospitality Homes

888-595-4678

[hosp.org](https://www.hosp.org)

- \$25 a night suggested donation
- Lodging for patient/families in private volunteer host homes



### **Ronald McDonald House at Boston Harbor**

250 First Ave., #318, Charlestown  
617-398-6458  
[rmbostonharbor.org](http://rmbostonharbor.org)

- Lodging for patient families in studio, one- and two-bedroom apartments
- Parking for one car
- Shuttle to Boston Children's

### **In the ICU**

The Medical-Surgical Intensive Care Unit (MSICU) and the Cardiac Intensive Care Unit (CICU) also have a bed available in the baby's room. The Neonatal Intensive Care Unit (NICU) does not. The ICU is not the most relaxing place to sleep and families often find they need a place away from the unit to relax. But if you feel the need to be close to your baby, you should know that there is the option in the MSICU and CICU for one parent to sleep at bedside. Once the baby transfers to the floor there are only bedside accommodations for one parent.

**IMPORTANT TIP:** Many of these services require you to complete an application for your anticipated stay, including your anticipated dates of travel and lodging. Please be sure that you ask about being added to the wait list if your dates are not available at the time of your initial request. The travel plans of families with medically complex children are always changing and rooms open up all the time.

## **Hotels**

### **The Inn at Longwood Medical**

342 Longwood Ave., Boston  
617-731-4700  
[innatlongwood.com](http://innatlongwood.com)

- Walking distance to Boston Children's

### **Best Western Roundhouse Suites**

891 Massachusetts Ave., Boston  
617-989-1000

- Free shuttle to Boston Children's
- Free parking

### **Hampton Inn & Suites**

811 Massachusetts Ave., Boston, MA 02118  
617-445-6400

- Free shuttle to Boston Children's, Logan Airport and area attractions

### **The Longwood Inn**

123 Longwood Ave., Brookline  
617-566-8615

- 21 rooms and a one-bedroom apartment
- Walking distance to Boston Children's
- Free parking

### **Holiday Inn Brookline**

1200 Beacon St., Brookline  
617-277-1200

- Free shuttle to Boston Children's

### **Marriott Courtyard Brookline**

40 Webster St., Brookline  
617-734-1393

- Ask for patient rate when booking
- Free shuttle to Boston Children's

## **Short-term furnished rentals**

The following is a partial list of sources for furnished rentals. Neighborhoods in proximity to Boston Children's include Longwood Medical Area, Fenway/Kenmore and Brookline.

[airbnb.com](http://airbnb.com)

[furnishedhousing.com](http://furnishedhousing.com)

[oakwood.com](http://oakwood.com)

[sublet.com](http://sublet.com)

[vrbo.com](http://vrbo.com)

**180 Brookline Ave., Boston**  
877-902-0832

**1330 Boylston St., Boston**  
877-902-0832

**Fenway Triangle Trilogy**  
180 Brookline Ave., Boston  
877-383-1237

**Greenhouse Apartments**  
150 Huntington Ave., Boston  
617-267-6777

- One-bedrooms starting at \$4,170
- Two-bedrooms starting at \$5,370.

### **Hancock Village Apartments**

298 Independence Dr., Chestnut Hill  
877-314-1472

- One-bedrooms starting at \$3,300
- Two-bedrooms starting at \$4,500
- Three-bedrooms starting at \$4,700.

### **Longwood Towers**

20 Chapel St., Brookline  
855-596-8125

- One-bedrooms starting at \$4,550
- Two-bedrooms starting at \$5,730

### **Longwood Galleria Apartments**

400 Brookline Ave., Boston  
617-566-5204

- Unfurnished, one-year lease required



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## Food and other necessities

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### Restaurants

#### Boston Children's Fresh Food Court

- Chef's Playground, Starbucks, Subway, Pizzeria Regina

#### Au Bon Pain

Boston Children's lobby

- Soups, salads, sandwiches and pastries

#### Red Mango

Frozen yogurt and smoothies

#### Galleria Food Court

342 Longwood Ave., Boston

- McDonald's, Subway, Dunkin', Beantown Burrito, T. Sushi Wraps and Noodles, etc.

#### Bertucci's

1 Blackfan St., Boston

- Italian cuisine and pizza

#### Boloco

283 Longwood Ave., Boston

- Burritos and smoothies

#### Brueggers

375 Longwood Ave., Boston

- Bagels, sandwiches, salads, and coffee

#### Cafe Nero

360 Longwood Ave., Boston

- European coffeehouse

#### J.P. Licks

1618 Tremont St., Boston

- Homemade ice cream and frozen yogurt

#### Longwood Grille

(in the Inn at Longwood)

342 Longwood Ave., Boston

- American cuisine

#### B. Good

360 Longwood Ave., Boston

- Kale and grain bowls, seasonal salads and all-natural burgers and sandwiches

#### Pret A Manger

360 Longwood Ave., Boston

- Homemade sandwiches, soups and salads

### Groceries

#### Star Market

33 Kilmarnock St., Boston

#### Stop and Shop (Brigham Circle)

1620 Tremont St., Boston

#### Peapod.com

Online grocery service with delivery from Stop and Shop.

- Minimum order \$60

#### Trader Joe's

1317 Beacon St., Brookline

#### Whole Foods

1028 Beacon St., Brookline

### Pharmacies

#### CVS

Boston Children's, Level 1

#### CVS

350 Longwood Ave., Boston

### Banks

#### Bank of America (ATM)

Boston Children's, Level 1, near Fegan elevators

#### Citizens Bank (ATM)

Boston Children's, Level 1, near Fegan elevators

### Postal Services

#### UPS Store

423 Brookline Ave., Boston

#### U.S. Post Office (near Brigham Circle)

1575 Tremont St., Boston



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## Insurance FAQs

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### How do I contact my insurance provider?

The number for member services is typically located on the back of your child's insurance card. You can also visit the insurance provider's website for more information.

### How much will my Boston Children's visit cost?

Co-insurance, co-payments and deductibles are determined by your insurance plan. We strongly encourage you to contact your plan directly to gain a full understanding of what you may owe.

In cases when we are considered an out-of-network provider or in a tiered network, you may be subject to increased out-of-pocket expenses. You should always verify your benefits and coverage limitations directly with your insurance before your visit.

You can request an estimate of the expected charges for the health care services provided by the hospital and its physicians during your visit. Please contact the CDH Program if you wish to obtain an estimate.

### What do all of these insurance terms mean?

There are multiple places to find definitions. A few suggestions include:

[healthcare.gov/glossary](https://www.healthcare.gov/glossary)

[cms.gov.CCIIO/Resources/Files/Downloads/uniform-glossary-final.pdf](https://www.cms.gov/CCIIO/Resources/Files/Downloads/uniform-glossary-final.pdf)

[hcfama.org/glossary-terms](https://www.hcfama.org/glossary-terms)

### Who do I contact if my child does not have active insurance?

If you have active insurance and wish for your child to be on your plan, contact your insurance provider directly to add them to your plan.

If your employer offers insurance, talk with them directly.

If you need to enroll in insurance through the federal marketplace visit [healthcare.gov](https://www.healthcare.gov) or call 800-318-2596.

### Who do I contact if I have questions about my insurance?

You can find local insurance assistance by visiting [localhelp.healthcare.gov](https://www.localhelp.healthcare.gov)

In Massachusetts, call 800-272-4232 for the Health Insurance Helpline through Health Care For All

### Other questions?

Please let us know, we'll help point you in the right direction.

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## Join our study

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For more than a decade, a dedicated team of researchers and clinicians from Boston Children's and MassGeneral Hospital for Children has worked together to better understand the genetics of CDH and associated disorders. This Boston-based study hopes to identify the genetic variations that cause these conditions. Ultimately, we hope this knowledge will lead to improved outcomes for future generations of babies born with CDH.

### What does participation in this study involve?

To participate, you will need to fill out a questionnaire and give us permission to review your child's medical records. If you live in the Boston area, we will ask to perform a brief physical examination of the family member or members with CDH. If you live outside the Boston area, we will ask permission to view their most recent genetic and physical examination records.

Since changes in genes are best detected by comparing samples between affected and unaffected family members, we will ask to obtain both a sample from those with CDH and those without it. Depending on the age, weight and health status of each person, we may obtain different types of samples, including blood, saliva, a tiny skin sample from surgery or a pathology specimen. If coming to Boston is inconvenient, your local caregiver can collect the samples and ship them to us for analysis. We will work with you and your doctor to coordinate this process.

Participation in our study only takes about one hour of your time. There are no costs to you or your insurance company for genetic analyses performed in this study or for sample collection, medical record retrieval or shipment. This study does not involve payment or compensation for you or your family.

To learn more, please contact Jennifer Lyu at 617-355-8780 or [cdhresearchstudy@childrens.harvard.edu](mailto:cdhresearchstudy@childrens.harvard.edu)



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## Contact numbers

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### **Boston Children's Hospital**

Maternal Fetal Care Center: 617-355-6512  
Hale Center for Families: 617-355-6279  
Hospitality Homes: 888-595-4678  
Inpatient Food Service: 617-355-3663  
Cardiac (CICU), 8 South: 617-355-8087  
Medical/Surgical (MSICU), 7 South: 617-355-8077  
Neonatal (NICU), 7 North: 617-355-8076  
International Health Services: 617-355-5209  
Interpreter Services: 617-355-7198  
Lactation Support: 617-355-0005  
Pastoral Care: 617-355-6664  
Patient Family Housing Reservations: 617-919-3450  
Patient Financial Services: 617-355-3397

### **Maternal care**

#### **Beth Israel Deaconess Medical Center**

Patient Registration: 617-754-8240  
Maternal Fetal Medicine: 617-667-4836

#### **Brigham and Women's Hospital**

Patient Registration: 866-489-4056  
Maternal Fetal Medicine: 617-732-4840

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## Further information

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Our team is happy to talk with you about details of your visit, clinical questions or needs specific to your family. Please call 617-355-6019 or email [CDHprogram@childrens.harvard.edu](mailto:CDHprogram@childrens.harvard.edu)

Please let us know if you have suggestions or additional information to include in this packet or tips for other families coming to Boston based upon your own experience.



**Boston Children's Hospital** | Congenital Diaphragmatic Hernia Program

This guide was created to help Boston Children's patients and families find and access resources. The CDH Program strives to make the information provided as timely and accurate as possible, but makes no claims, promises, or guarantees about the accuracy, completeness, or adequacy of the contents.