

Vermont Family
Network (VFN)
600 Blair Park Rd.,
Ste. 240
Williston, VT 05495
1-800-800-4005

Children with Special
Health Needs (CSHN)
108 Cherry St.,
PO Box 70
Burlington, VT 05402
1-800-660-4427

UVM Children's
Hospital
111 Colchester Ave.,
Main Campus,
East Pavilion, Lev. 4
Burlington, VT 05401
1-802-847-8200

Boston Children's
Hospital (BCH)
300 Longwood Ave.
Boston, MA 02115
1-617-355-6000




Travel Guide for Vermont Families Receiving Services from Boston Children's Hospital (BCH)

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Planning for your child's stay at BCH

There are many people that you can help you in preparing for an upcoming hospital stay and all the details to be considered.



Some of these people are:

- The medical specialist that referred your child for care at BCH
- The care coordinator at your child's pediatricians' office
- A CSHN Medical Social Worker (MSW) can offer resources, supports, and help with: **800-660-4427**
 - ♦ Medicaid Insurance
 - ♦ FMLA paperwork
 - ♦ Hard conversations and emotional support
 - ♦ Financial resources: potential grant opportunities, gas cards, cafeteria cards/meal vouchers
 - ♦ Hospital happenings such as special dinners, massage, music therapy, Reiki, meditation, yoga etc.
- A case manager through other agencies: such as the designated agency, Pediatric Palliative Care, Children's Integrated Services or Community Health Team
- If your child is on an IEP (Individualized Education Plan) have a conversation with your child's special educator about your child's educational needs during the hospital stay and recovery
- Contact Vermont Family Network about: **800-800-4005**
 - ♦ Parent to Parent - You can be confidentially matched with another parent who has shared similar experiences and/or diagnoses. VFN connects families with other families for caring and support.
 - ♦ Medically Necessary Funding- Income eligible families of children with special health needs may apply for \$1,000 per 12 month period for unmet medically necessary needs such as equipment, medications, travel, and therapies.
 - ♦ Care Notebook- a place to record all information regarding your child's medical happenings.
- FMLA (Family Medical Leave Act)- allows employees 12 weeks of unpaid time off from work to care for an immediate family member that has a serious health condition, without jeopardizing employment status. The Department of Labor can provide more information.

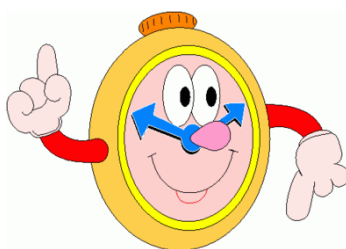


If your child's BCH admission is an emergency, contact your Medicaid Transportation Broker as soon as possible—Call on your way to the hospital, if possible.
-See page 4 for more details.

If you have time for additional planning...

It would be helpful for you to call a meeting with your child's care team. Having everyone in one room to discuss your child's medical care and answer any questions that you have can be very valuable.

* Request one of the care team members to make a connection with the BCH social work department for you.



You should leave this meeting knowing whom you can contact with questions while you are at BCH.

You will be given a packet of information once you get to the hospital. This will include BCH contacts, hospital logistics, and surrounding area attractions and eateries.

What about insurance?

If you have private insurance, call the number on the back of your child's insurance card to ask any medical coverage questions you have. Ask if your child would qualify for one of their nurse case managers. This person will be an important contact if coverage questions or issues come up. Be sure to ask if your insurance includes coverage for mileage and lodging.



Vermont Medicaid Insurance

A Medical Social Worker can help you start or complete an application to determine eligibility for Medicaid. A child may receive Medicaid insurance based on either income or disability.

Dr. Dynosaur is determined based on household income and applied for through Vermont Health Connect.

Disabled Children's Home Care (DCHC) or Katie Beckett determination is based on the *child's* income and disability/condition. This is a paper application and will only begin after the birth of your child. You can begin the DCHC application before your child's birth and bring it with you to BCH to finish after your child is born. You can include medical documentation such as reports from surgeons and specialists. You can also send a copy of the hospital discharge summary but get the application in as soon as possible. The medical reviewers may request missing medical documents to complete their determination.

Additional ways to qualify for Medicaid can be found in VFN's *Six Ways to Access Medicaid*.

Search: vermontfamilynetwork.org then navigate to: Services & Support tab, Health>, Accessing Health Care, Six Ways to Access Medicaid

Medicaid transportation, lodging, & food expenses

In addition to insurance coverage, Medicaid may help with some travel expenses to and from Boston such as: cost of fuel, meal expenses, parking, and lodging.

BCH is an out of state and not a Medicaid In-Network hospital. When utilizing Medicaid, the request process requires extra steps. All Medicaid Transportation calls should be made to Vermont Public Transportation Association (VPTA): Toll free **833-387-7200**.

You will need to call initially to sign up for the program and complete the required registration forms.



Your child's primary doctor or referring specialist has to fill out the Out-of-Area/ Out-of-State Transportation Physician Referral Form and send it to Department of Vermont Health Access (DVHA) for prior approval **at least TWO weeks before** your child's appointment. This form is used for outpatient office visits and inpatient hospital stays.

- On the Physician Referral Form, the doctor will need to check **Yes** ☒ if lodging is necessary. Medicaid generally pays for overnight (least costly, medically appropriate) lodging for appointments before 10am and when your child is in the hospital.

- It is recommended that you follow up with your child's doctor to confirm the Physician Referral Form and the Clinical Prior Authorization have been completed and sent to DVHA. Your child's BCH transportation request cannot be approved until both have been approved.



- Once the Physician Referral Form has been approved your Medicaid Transportation Broker will contact you about the trip and any further information they need. The broker will let you know when travel and lodging is in place.



- If you do not have a car, your car is not operating, your partner needs the only car, or you have any Medicaid Transportation questions you need to contact VPTA and complete the Medicaid Transportation Exception Request Form.



833-387-7200

- Medicaid will provide rides to Medicaid-billable appointments for eligible members only when there is no other means of transportation available. Members are eligible for the least costly, medically appropriate means of travel.

- Save all receipts as other trip-associated costs such as tolls and parking maybe reimbursed.
- You and your child (with prior approval) may receive reimbursement for meal expenses during your stay at BCH. See chart below:

Meal reimbursement rates:			
Per Meal	In State	Out of State	
Breakfast	\$5.00	\$6.25	You must leave your home before 5:30am
Lunch	\$6.00	\$7.25	Only after overnight stay or you are 6 hrs. away
Dinner	\$12.85	\$18.50	Returning home after 6:30pm only

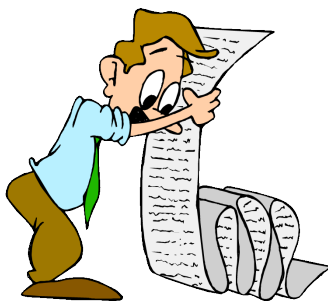
- Hardship Mileage Program- Medicaid will reimburse members using their own vehicle for medical trips totaling more than 50 miles per week or more than 215 miles per month.

DVHA will review all hardship requests to determine true economic necessity. Medicaid eligibility income guidelines will be used for all out-of-state transports, specifically the 300% Federal Poverty Level guideline as a limit for assistance.

How to be reimbursed for travel expenses...



You are responsible for completing the mileage form and keeping copies of your itemized receipts for lodging, meals, fuel, and tolls. You will need to get the mileage form to the Medicaid Transportation Broker within 30 days of your return home.



- Medicaid will only reimburse a food receipt that is itemized.
- You will not be reimbursed from a receipt that only states the total amount of the meal.
- You will not be reimbursed for grocery store or convenience store purchases.

Additional transportation resources



Rapid Transit (MBTA or the T)

621-222-3200

To get to BCH, take the D or E Green Line to Longwood. Follow Longwood Avenue to BCH.
—> **See** Rapid Transit map, back of booklet.

Angel Flight

800-549-9980

Angel Flight arranges free flights for those requiring access to medical care.

Patient Airlift Services (PALS)

631-694-PALS(7257)

Volunteer medical flights and free air transportation.

Parking at BCH Patient Family Garage (24 hour)



Located at: the corner of Longwood Ave and Blackfan St. across from Bertucci's Restaurant. Expect congested traffic between 7-9am and 4-6pm; leave extra time for travel and parking.

Parking tickets can be validated at the BCH Main Lobby reception desk or Emergency Services (for emergency patients only). A limited number of clinics have validators located in their reception areas.

Discounted parking rates: validated parking available for maximum fee of \$10 for up to 24 hrs. for parents.

Family Extended Stay Parking: \$60 week-long card can be purchased at the BCH parking office (\$10 discount). The parking pass allows you to come and go as needed during that period without having to stop at the cashier station.

Take Note:

If the Patient Family Garage is full, ask the BCH reception desk about alternative parking. **Also**, if you have a mid-size SUV with a Thule or carrier on top it will not fit in the garage. You can park in valet or park in an alternative location.

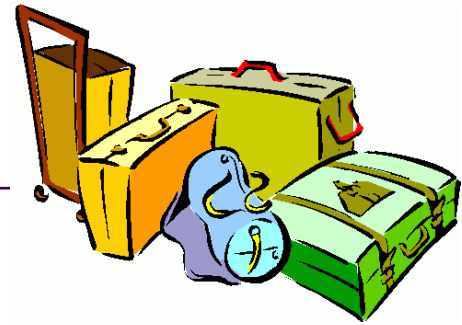
BCH valet services

For \$5 plus the normal garage fee, there is 24 hour valet parking available at the main entrance of the hospital.



The \$5 fee is waived for vehicles with a handicap placard but you must pay the normal garage fee.

What should we pack?



- Laundry detergent (pods are very easy to travel with). Detergent is not sold in hospital and is expensive at the CVS
- Tide to Go Instant Stain Remover in case you need to do a quick wash of something in your room
- Comfortable clothes
- Sneakers
- Slippers/slip on shoes to wear in the room; great when you need to get up quick
- Warm clothes (ICU can be cold)
- A sleeping pad
- Bring your VFN Care Notebook or a note book to write down any questions you have for the doctors/nurses and to record your child's medical visit details
- Baby wipes- some hospital floors use dry pads that you have to wet with water. If you prefer wipes then it would be best to bring a package with you
- Your child's favorite items
- Cash and quarters for parking, interstate toll, and laundry



How to reduce some of that travel stress

Plan your travel course ahead of time.

Program your GPS with your travel destination address. And/or, bring a map to use for reference while traveling.

Keep cash ready for upcoming toll booths.

Is there an affordable lodging option when my child is a patient?

Accommodations in Boston are very expensive, BCH provides a few options for patient families that are less expensive. Please discuss these options with your Medicaid Transportation Broker.

Parent Sleep Spaces, Farley 5 and 6
Hale Family Center for Families
No charge, reservations required, limited availability/26 spaces
617-355-6279

The hospital provides accommodations in the Medical/Surgical Intensive Care Unit (MICU), Newborn Intensive Care Unit (NICU), and Cardiac Intensive Care Unit (CICU) for one parent in each patient's room, which is usually a fold down chair or a bed built into an alcove, linens are provided. Communal kitchen and laundry facilities are available.

- Shower facilities are available on each inpatient unit except for the ICUs.
- Your child's nurse can direct you to the nearest shower facility.



Ronald McDonald House
229 Kent Street, Brookline, MA 02446
\$10/night or \$200/month
617-734-3333

Accommodation for families and patients receiving **oncology** treatments. Patients must be under 21 year's old, receiving treatment for cancer or other life-threatening hematological diseases and must live more than 30 miles outside of Boston.

BCH Patient and Family Housing
Application required in advance, on-line
\$30 a night
617-919-3450

Within walking distance of BCH are two wheelchair accessible housing options for any family member or support person of a patient. There is a communal kitchen, living rooms, bathrooms, linens and towels supplied, free wifi and free laundry facilities. A breast pump is available for nursing mothers. There is a free shuttle bus that runs between the housing and BCH.

The Yawkey Family Inn
241 Kent Street
Brookline, MA 02446

The Devon Nicole House
21 Autumn Street, 5th Floor
Boston, MA 02215

Hospitality Homes Program
Free but there is a \$25 cancellation fee
*Application plus two references required
1-888-595-4678

Temporary housing in private volunteer host homes and other donated accommodations for families and friends of patients.

Additional accommodation options



The hospital will supply a list of Patient Resources list for area hotels, inns, bed and breakfasts, and short-term housing. **617-919-3450**

*Ask for patient rate/BCH discount when booking. If needed, ask your Medical Social Worker for a letter of verification of patient status.

Hotels:

Inn at Longwood Medical, 0.01 mi. to BCH
342 Longwood Avenue, Boston, MA 02115
617-731-4700

Fridge and microwave available
Overnight parking \$18.00 per day

Four Seasons Hotel, 2.79 miles to BCH
200 Boylston Street, Boston, MA 02118
617-338-4400

Fridge and microwave available
Overnight parking \$41.00 per day,
complimentary drop off car service

enVision Hotel, 0.9 miles to BCH
81 South Huntington Avenue, Boston, MA,
02130
617-383-5229

Fridge and microwave in room
Pet Friendly
\$25 parking per night

Homewood Suites by Hilton Boston/
Brookline, 1.9 miles to BCH
111 Boylston St, Brookline
617-232-1487

Full kitchen, free breakfast
Valet parking only \$35/night

Holiday Inn Brookline, 0.75 miles to BCH
1200 Beacon Street, Brookline, MA 02446
617-277-1200

Fridge and microwave available
Free parking, free shuttle (7-10am, 11-
10pm, inquire about estimated travel time)

Marriott Courtyard Brookline, 1.30 miles
from BCH
40 Webster Street, Brookline, MA 02446
617-734-1393

Fridge and microwave available
Overnight parking \$15.00, free shuttle

Long Term Housing:

Church Hill Company- Rental Apartments
866-255-0593

Ask the hotel if they provide a free shuttle to the hospital.

Maternal-Fetal Medicine at Brigham and Women's Hospital (BWH)

Some expecting mothers travel to BCH for fetal intervention or for the care of their baby immediately following delivery. Whether the transfer of mother's care is temporary or for the duration of the pregnancy, providers specialize in the care and delivery of high risk pregnancies and they partner with BCH for fetal interventions.

BWH Registration: 866-489-4056

Preregistration is required before a transfer to BWH. They will provide a registration number for when you make an appointment.

Scheduling Appointments: 617-732-4840

Be prepared to provide your registration number.

Birthing Support/Doula:

BCH and BWH do not provide Doulas. There are local Doulas willing to travel to provide birthing support.

Birthing Gently 978-314-5533

Rising Tide 774-207-7124

Driving to BWH:

75 Francis Street, Boston, MA

Valet parking available at main entrance or patient parking at 70 Francis Street, Boston, MA.

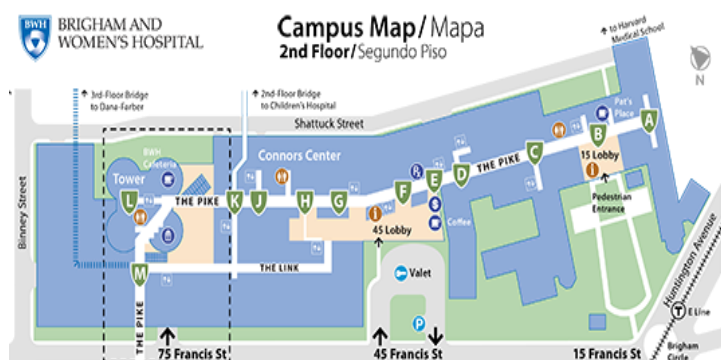
Walking from Advanced Fetal Care Center (AFCC) at BCH to BWH:

Turn right out of AFCC, follow hall, enter the sliding doors to the indoor bridge. Cross to the bridge which enters into 2nd Floor of BWH.

Locations within BWH from bridge:

To Maternal-Fetal Medicine, turn left on the Pike, take elevator on left to 3rd floor.

To OB admitting, turn right on the Pike, take stairs to ground floor. Admitting is past escalator on right.



To Triage/Labor and Delivery, turn left on the Pike, take elevators on left to 1st floor. Ask security to release elevator to 5th floor.

Lactation Supports:

Throughout the hospital lactation rooms and breast pumps are available, inquire at the check-in desk. All pumps are hospital grade. Lactation consultants are ready to support nursing moms. Ask your child's nurse or social worker to make an appointment.

There potentially is a wait for the breast pump, you can arrange for a personal pump to cut down any wait time. The starter kit which has all new tubing and the essentials will cost \$50. A lactation vending machine is located outside of Au Bon Pain next to the elevators.



The essentials in Boston: meals, money, mail...

The hospital offers many dining options. Meal vouchers are available for purchase from the cafeteria, allowing you to order food from the menu in your child's room. Call 5food to order. Nursing mothers receive three free meal vouchers a day.



Children's Hospital Cafeteria
Farley Basement, BCH

Hours:

Monday-Friday: 6:30-10:30 am, 11-8pm

Weekends/Holidays: 6:30-10:30am, 11- 7pm

Au Bon Pain

Main Lobby, BCH

Hours:

Sunday-Thursday, 24 hours a day

Saturday and Sunday, closes at 11pm

JP Licks

617-566-6676

1618 Tremont Street, Boston, MA

Homemade ice cream and frozen yogurt

Longwood Grill at Inn at Longwood Medical

617-232-9770

342 Longwood Avenue, Boston, MA

American cuisine

B. Good

617-232-5599

360 Longwood Ave, Boston, MA

Kale and Grain bowls, salads, sandwiches

Starbucks

617-277-5202

383 Longwood Avenue, Boston, MA

Coffee, baked goods and sandwiches

Restaurants connected to hospital:

Galleria Food Court

342 Longwood Avenue, Boston, MA

McDonald's, Subway, Dunkin Donuts,

Beantown Burrito, plus a few more

Restaurants within walking distance:

Bertuccis

617-739-2492

1 Blackfan Circle, Boston, MA

Italian cuisine and pizza

Boloco

617-232-2166

283 Longwood Avenue, Boston, MA

Burritos and smoothies

TGI Fridays

617-734-1047

1626 Tremont Street, Boston, MA

American cuisine

Uno Chicago Grill

617-262-4911

645 Beacon Street, Boston, MA

American cuisine and pizza

Brueggers

617-232-2166

375 Longwood Avenue, Boston, MA

Bagels, sandwiches, salads, and coffee

ATMs:

Located at 1st floor BCH,

near Fegan elevators:

Bank of America ATM

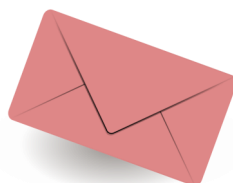
Citizens Bank ATM



The essentials in Boston- continued

Postal Service:

UPS Store
617-738-3372
423 Brookline Avenue,
Boston



US Post Office (near Brigham Circle)
1575 Tremont Street, Boston

Grocery Stores:

Shaws
617-267-4684
33 Kilmarnock Street, Boston,
MA



Stop and Shop (Brigham Circle)
617-232-3572
1620 Tremont Street, Boston, MA

Trader Joe's
617-278-9997
1317 Beacon Street, Brookline, MA

Target
617-991-8262
1341 Boylston Street, Boston, MA

Pharmacy:

CVS (Pharmacy only)
1st floor of BCH
617-975-3500



CVS
617-731-5753
350 Longwood Avenue, Boston, MA

Walgreens
617-232-7506
429 Brookline Avenue, Boston, MA

Where can I send a fax or find a computer to access my e-mail?

The Center for Families is located in the Farley building, room 111.

Here you will find access to:

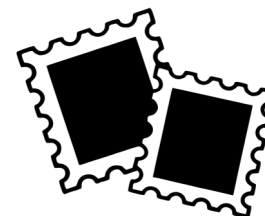
- Computers and Printers
- Copy/Fax machine
- Video phone
- Library



Is there someplace where I can buy stamps or cash a check?

There is a cashier (located on Farley 1, across the hall from the Center for Families) who sells stamps and cashes traveler's checks, money orders, personal checks up to \$25.00.

Hours:
Monday-Friday,
8am to 4:30pm
857-218-3434



Additional hospital supports

Child Life Specialists

617-355-6551

You can ask for a Child Life Specialist if one has not visited your child during your stay.

Their purpose is to:

- Help patients develop ways to cope with fear, anxiety, separation and adjustment to the hospital experience giving special consideration to each child's family, culture, and stage of development.
- Provide consultation to the health care team regarding developmental and psycho-social issues
- Provide preparation and individualized support before and after medical procedures
- Facilitate developmentally appropriate play, including medical play, at the bedside, in activity rooms and in clinic areas
- Initiate tutoring services



Is there a location to do my laundry at BCH?

Coin operated laundry is located on the 1st Floor of the Farley Building.



Security Escort 24 hr. availability

617-355-6121

Within 15 minutes, a patient and family can be escorted by a security officer within certain areas of the hospital.



Chaplaincy

617-355-6363

Chaplains are in the hospital every day from 8am-5 pm and available after hours for emergencies. Ask your nurse for this service.

Interfaith Chapel, Farley 1 near the Cashier's Office

617-355-6664

A peaceful interfaith chapel welcome to you and your family to use for your own prayers or meditation. Rosaries, electric Sabbath candles, prayer rugs and cushions, and scriptures in many languages are available upon request. Schedule of services is posted at the entrance.

The chapel hosts regular weekly observances and services on special religious holidays. These include Catholic mass, Sabbath candle-lightings, and Buddhist meditation. The Muslim chaplain can provide directions to local institutions for Friday prayer, Ramadan, and other holy days.

Useful contact information

Vermont Family Network (VFN)
Williston, VT
1-800-800-4005

CSHN Main Office Number
Burlington, VT
1-800-660-4427

UVM Children's Hospital
Burlington, VT 05401
1-802-847-8200

Boston Children's Hospital (BCH)
300 Longwood Avenue, Boston, MA 02115
1-617-355-6000

Hale Family Center for Families- Patient Relations: for any questions about your child's care, hospital policies, and procedures.
1-617-355-7673

Mission statements:



VFN's mission is to empower and support all Vermont families of children with special needs.

CSHN is a public health program for families, health care providers and communities. CSHN supports Vermont children and youth with special health needs by ensuring comprehensive, community-based and family-centered services.

BCH Provide the highest quality health care. Be the leading source of research and discovery. Educate the next generation of leaders in child health. Enhance the health and well-being of the children and families in our local community.

UVM Children's Hospital's mission is to improve the health of the people in the communities we serve by integrating patient care, education, and research in a caring environment.



How do I talk effectively with my child's doctors and nurses?

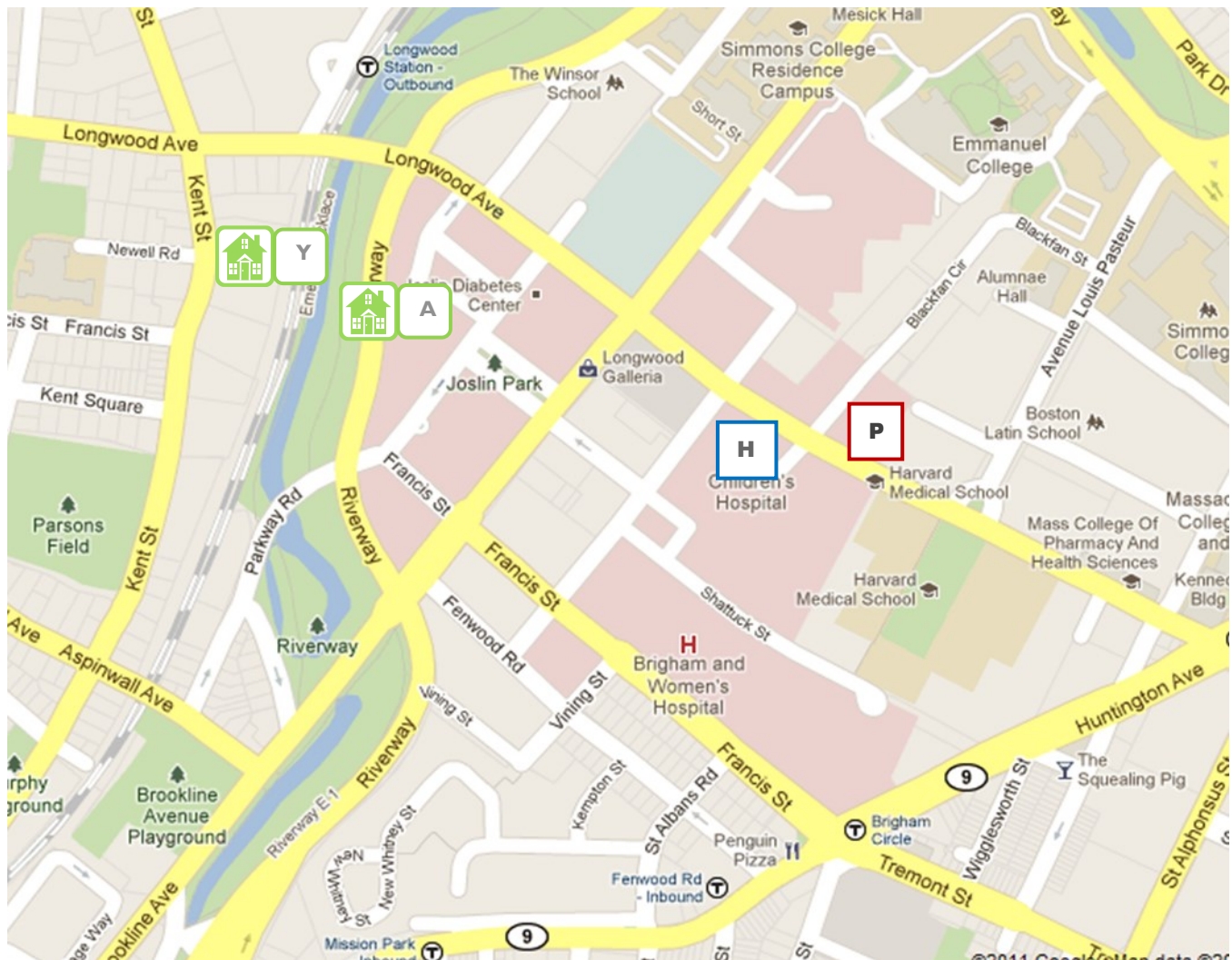


Some helpful resources are:


Effective Communication in Children's Hospitals - A Handbook of Resources for Parents, Patients, and Practitioners

Talking with Your Child's Doctor - Information on how to maximize your time with your child's doctor.


Finding your way in the neighborhood



H Boston Children's Hospital
300 Longwood Ave., Boston

 **A** The House at 21 Autumn St.

P Children's Hospital Parking
The corner of Longwood Ave.
& Blackfan St.

 **Y** Yawkey Family Inn
241 Kent St.

T Subway stop (MBTA or the T)



Tear off these last two pages, keep the maps handy during your travels for easy reference.

Be ready for your travels with cash and quarters on hand for: parking, tolls, subway/bus fare.



Massachusetts Bay Transportation Authority Rapid Transit/Key Bus Routes Map



Legend

- RL** RED LINE
- M** MATTAPAN LINE
- OL** ORANGE LINE
- BL** BLUE LINE
- SL** SILVER LINE and branches
- GL** GREEN LINE and branches
- COMMUTER RAIL**
- KEY BUS ROUTE**
- FERRY**
- Accessible station**
- Rapid Transit transfer station**
- Commuter Rail transfer station**
- Free Logan Airport shuttle bus**
- Amtrak service**
- Customer Communications & Travel Info**
- MBTA Transit Police: 911**
- Elevator/escalator/lift updates: 800-392-6100**

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Not to scale

Take D or E Green Line to Longwood ★ Follow Longwood Avenue to BCH.