

Thank you for your interest in giving back to Boston Children's Hospital by getting involved. We welcome you to explore the many ways to support us in our efforts to provide the very best care for children and their families. This guide describes some of the exciting ways you and your family can contribute.

We hope this information helps connect you with an opportunity that works best for you.

Please visit Boston Children's website to learn more about our Family Partnership Programs, including our Family Advisory Council and Family-to-Family Program: www.childrenshospital.org/patient-resources/family-partnerships.

If you have any questions, ideas or concerns, please email familypartnerships@childrens.harvard.edu.

BECOME A FAMILY PARTNER

Background: Family Partners are people who want to find ways to be involved in Boston Children's, but may not be available on a regular schedule. Family Partners often:

- Help in workgroups (usually a mix of family members and employees working together on a project)
- Take surveys (in person, online or by phone)
- Share their ideas in interviews or focus groups (in person, online or by phone)

Time Commitment: Varies. Some workgroups last for a short time while others may last for months—or even years! Some workgroups may ask interested family partners to come to meetings in person, while others are OK with partners participating by phone. You can leave a workgroup at any time. Surveys or interviews are often done online or by phone and usually take less than an hour. Focus groups are usually in person and 1 or 2 hours. Our Family Partnership staff can help to find you opportunities that work best with your schedule.

How to Become a Family Partner: Please fill out this form:

<u>https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=Je4cvE</u>. A staff member will contact you to set up a time to talk by phone. Based on your Boston Children's experience and interests, we'll match you with opportunities as they come up. Please note that this may take several months.

BECOME A VIRTUAL ADVISOR

Background: Boston Children's Virtual Advisors Program is a way for families to share ideas and give constructive feedback from the comfort of their own homes. Virtual Advisors do not have to live near Boston or have to commit a lot of their time. We usually post content online every 1-2 weeks for members to review and respond to. The Virtual Advisors Program is not a support group—it's a working committee. Virtual Advisors may use their own personal experiences to make points, but we ask them to keep the focus more general. Also, we ask virtual advisors not to post detailed medical information about their child.

Time Commitment: Extremely flexible. You can log on to the site whenever you want to!

How to Become a Virtual Advisor: Please fill out this form

<u>https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=Je4cvE</u> and let us know that you want to be a Virtual Advisor. A member of our staff will contact you and give you a Privacy and Confidentiality Agreement to sign. Once that's complete, we'll teach you how to log onto the site.



JOIN THE FAMILY ADVISORY COUNCIL

Background: The Family Advisory Council (FAC) is made up of 20 parents of Boston Children's patients as well as several Boston Children's staff members. The FAC's goal is to make sure that patients and families are at the center of every major decision made at the hospital that affects the quality of care, safety or the patient/family experience. Members are key parts of our organization. They serve on boards and committees and build meaningful, long-lasting partnerships with hospital leaders. Like the Virtual Advisors Program, the FAC is not a support group—it's a working committee. FAC members engage with the hospital in 3 key ways:

- Advise/share: Provide feedback at monthly council meetings and in focus groups, workgroups and committees
- Partner/support: Participate in important hospital committees that are focused on the strategic and corporate goals of Boston Children's
- Drive/lead: Direct projects, including working closely with several hospital departments
- Read about some FAC accomplishments by <u>clicking here</u>.

Time Commitment: Monthly FAC meetings are either Tuesday or Wednesday evenings from 5:30-8 p.m. at Boston Children's Main Campus. We ask members to come in person, but allow for them to join by phone if they cannot come to a specific meeting. FAC members join workgroups and committees in between meetings. Workgroups usually require 1-3 hours of additional volunteer time a month.

How to Join the Family Advisory Council: We welcome you to talk to us about joining the FAC, and new members officially join twice a year after an orientation. If you're interested in joining, please fill out this form https://redcap.tch.harvard.edu/redcap edc/surveys/?s=Je4cvE and let us know about your interest in the FAC. A staff member will interview you. If it's a match, you'll begin a process that includes: an application; interviews with FAC members and hospital staff; a Volunteer Services orientation; and a Family Partners orientation. To be on the FAC, you'll need to receive a flu shot each year.

BECOME A FAMILY-TO-FAMILY MENTOR

Background: The Family-to-Family Program matches people who have had specific kinds of medical experiences with other Boston Children's patients or families going through similar challenges. Mentors provide insight but do not share medical advice. These mentorships are usually by phone and last for just 1-2 phone calls.

Time Commitment: This is not a long-term mentorship.

How to Become a Family-to-Family Mentor: Please fill out this form

https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=Je4cvE
and a staff member will contact you.
Based on your medical experience and interests, we'll see if you're a match for the program. If you are, you will take an in person, 4-hour training about how to be a mentor.



BECOME A TEEN ADVISORY COMMITTEE MEMBER

(For patients and siblings)

Background: The Boston Children's Teen Advisory Committee (TAC) is a group of about 20 Boston Children's patients and their brothers and sisters. Several hospital staff members lead it. This group finds ways to improve the patient and family experience in new ways each year. Members work on many projects, including those with hospital's Government Relations office, the Patient and Family Education team and the Social Work Department Transition Committee.

Time Commitment: The TAC meets once a month, on Thursday evenings from 5-7 p.m. on Boston Children's Main Campus. TAC members serve on the council for a school year. There are 11 meetings a year.

How to Become a Teen Advisory Council Member: Teens can join during their freshman or sophomore year of high school. They may continue through their senior year in college. If you or your child is interested in joining, please fill out this form https://redcap.tch.harvard.edu/redcap edc/surveys/?s=Je4cvE and a staff member will contact you. Based on your Boston Children's experience and interests, we'll see if you're a match for the committee.

ENGAGE LATINO PATIENTS AND FAMILIES

Background: Boston Children's has many Spanish-speaking patients and family members from around the world. There are a many ways to give back through this group. Latino patients and family members serve on workgroups and help with special projects to find ways to improve the Latino patient and family experience, give feedback and help other Latino families at the hospital.

Time Commitment: Flexible with your schedule.

How to Get Involved: Contact Cecilia Matos, patient and family educator in the Hale Family Center for Families, at (617) 355-3196 or cecilia.matos@childrens.harvard.edu.

BECOME A VOLUNTEER TEAM MEMBER

Background: Through our Volunteer Services Programs, you can give the gift of your time on a weekly hasis

Time Commitment: Volunteers work at least 1, 4-hour shift a week for 1 calendar year. During the summer, high school students ages 16-18 can be weekly volunteers over 2 back-to-back summers in the Summer Teen Program.

How to Get Involved: Visit the Volunteer Services webpage: www.childrenshospital.org/ways-to-help/volunteer-services. For special assignments where volunteers may be needed (for example: cultural navigators), visit this webpage: www.childrenshospital.org/ways-to-help/volunteer-services/special-assignments.



COOK A MEAL FOR FAMILIES

Background: Boston Children's Patient Family Housing Program provides affordable housing for up to 35 families while their children are getting care at the hospital. The housing is at 2 locations: the Yawkey Family Inn (in Brookline, a few blocks from the hospital) and the Devon Nicole House (on Autumn Street, a few blocks from the hospital). You're welcome to bring a meal for these families.

You can decide if you want to cook a breakfast, lunch or dinner. Then, you have the option to:

- Cook onsite (each house has a kitchen)
- Have a restaurant deliver food
- Prepare a meal at home and bring it in

You're welcome to bring any kind of food. We just ask that you let the coordinators of each house know the ingredients ahead of time. Both houses are open 8 a.m.-10 p.m. Yawkey Family Inn's kitchen is big enough for 10 people to cook together and the Devon Nicole House's kitchen can hold 5 cooks.

How to Sign Up to Cook a Meal: Contact Caroline Raymond at the Yawkey Family Inn at (617) 919-3456 or Heather Foley at the Devon Nicole House at (617) 355-7577. Or email FamilyHousing@childrens.harvard.edu to find available dates and times.

GET INVOLVED WITH THE BOSTON CHILDREN'S HOSPITAL TRUST

Background: Team up with Boston Children's Trust to engage in fun and exciting fundraising opportunities raise money to benefit Boston Children's patients and families. The donations through the Trust provide assistance to things like research, care and patient services.

How to Get Involved

• Community Fundraising: Host an event in your community, such as a golf tournament or even a lemonade stand. The sky's the limit!

Website: www.bostonchildrens.org/fundraisers

Contact: events@chtrust.org

 Miles for Miracles Patient Partner Program: Miles for Miracles pairs a patient with a runner for marathon events. It gives runners motivation and inspiration, and gives patients and their families a unique chance to be a part of the marathon excitement in a highly personal way.

Website: www.bostonchildrens.org/milesformiracles

*Each race on the right-hand column has a specific patient partner application.

Contact: run@chtrust.org

 Milagros para Niños: Led by our Latino Advisory Council, Milagros para Niños raises funds for Boston Children's programs that serve underserved children, especially within the Latino community.

Website: www.bostonchildrens.org/milagros Contact: michael.bornhorst@chtrust.org



GET INVOLVED
WITH THE BOSTON
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(continued)

• Eversource Walk for Boston Children's Hospital: The Walk helps fund the exceptional care and groundbreaking research at Boston Children's. It's a family day event—and we love having new walk teams! Our next walk is on Sunday, June 12, 2016, at the DCR Hatch Memorial Shell.

Website: www.bostonchildrens.org/walk

Contact: walk@chtrust.org

Mix 104.1 Radiothon: For 2 days a year, the Mix 104.1 Cares for Kids Radiothon fills the Boston
airwaves with amazing stories of courage and hope from patients, families and staff at Boston
Children's. The broadcasting takes place in the hospital.

Website: www.bostonchildrens.org/radiothon

Contact: mixradiothon@chtrust.org

Time Commitment: Most opportunities take an hour or 2 of your time. You can get involved in longer-term projects as your schedule allows.

TELL YOUR STORY

Background: Your family's story may be instructive and inspiring to others. Boston Children's has three blogs that highlight our patients:

- The <u>Thriving blog</u>, read by parents and families, often features stories about children's and families'
 health journeys and gives health information and parenting advice. These can be written by patients,
 parents or Boston Children's staff (after an interview). Thriving stories include photos—sent by families
 and/or taken by staff photographers.
- The <u>Vector blog</u>, read by a science-curious audience, features stories of "citizen scientists"—families
 actively engaged in further research around their child's condition. These can be first person or staffwritten, and also may include family photos.
- The <u>Notes blog</u> is read by primary care providers and other health care professionals. Caregivers can speak directly to a clinical audience through first-person pieces, along with photos.

Time Commitment: This depends on whether you write the story yourself (more time-consuming but often the most popular), or simply have an interview. Interviews should last no more than an hour, and then you'll get a chance to review and comment on the blog post in draft form.

How to Get Involved: Please contact Boston Children's Marketing and Communications at marketing@childrens.harvard.edu. In your email, please let us know which blog you think is the best fit for your story.



Join the Child Advocacy Network (CAN) Background: Founded in 2000, the Child Advocacy Network (CAN) is a way to bring together staff, patients, families, volunteers, clinicians, community members, and anyone passionate in child health advocacy. Since its beginning, the CAN has been a catalyst for grassroots advocacy pertaining to child health and overall well-being. This includes healthcare access, mental health, injury prevention & public health, oral health, and more. The CAN has been a valuable resource to the Office of Government Relations, which works on a city, state, and federal level to speak out on the needs of children. The Office of Government Relations works closely with partners within the institution as well as community partners to develop a legislative agenda that improves the lives of children, and aligns with the hospital's four part mission of clinical care, research, community, and teaching. The best advocates are parents like you, who can share their stories to help influence policy that will have a positive impact on other children and families.

How to get involved: We rely on CAN members to be a powerful voice for children as public policy decisions are made. CAN members speak up for kids by writing letters, sending emails, making phone calls, and sharing their stories with legislators.