



Proton Beam Therapy in the United States: What you need to know

For patients, caregivers and family members for whom out-of-country proton beam therapy (PBT) has been recommended

Key points:

- At this time, PBT is not available in the province of Ontario.
- Ontario physicians may apply to the Ministry of Health and Long-Term Care (MOHLTC) Out-of-Country Prior Approval Program for funding for their patients to receive PBT in the U.S.
- PBT uses protons to deliver radiation therapy rather than photons used in conventional radiation therapy. PBT treatment could improve primary disease control, minimize normal tissue damage, and lead to reduced radiation-induced side effects.

This booklet has information to help you learn more about going to the U.S. for PBT, including:

- A. Quick U.S. essentials checklist (pg. 2)
- B. Things to know before receiving PBT in the U.S. (pg. 3)
- C. Checklist for patients (pg. 7)
- D. Checklist for caregivers (if applicable) (pg. 11)
- E. Important contacts and additional resources (pg. 12)



A. QUICK U.S. ESSENTIALS CHECKLIST:

- Out-of-Country approval letter from the MOHLTC
- Adult caregiver
- For children under 18, written letter from both parents that gives permission for travel
- Valid passports
- Travel medical insurance
- Medications
- U.S. money
- Credit card

Important to note:

Valid passports, travel medical insurance and medications are needed for both the patient and the caregiver (if applicable).



B. THINGS TO KNOW BEFORE YOUR PBT

Why would I/my child go to the U.S. to have PBT?

If you/your child are/is being offered PBT in the U.S. it is because:

- You/your child have/has a life-threatening disease and PBT is a recommended treatment option.
- PBT is not available in Ontario.

Though it might be the recommended treatment option, you/your child can choose conventional radiation therapy in Ontario. Talk to your/your child's physician about the differences between PBT and conventional radiation therapy.

Which U.S. facility will I/my child go to?

You/your child's referring physician can choose one of the following facilities for PBT in order for the services to be funded under OHIP:

Paediatric services:

Cincinnati Children's Hospital, Cincinnati, Ohio

Massachusetts General Hospital, Boston, Massachusetts

Northwestern Medicine Chicago Proton Center, Warrenville, Illinois

University of Florida Proton Therapy Institute, Jacksonville, Florida

Adult services:

Northwestern Medicine Chicago Proton Center, Warrenville, Illinois

University of Florida Proton Therapy Institute, Jacksonville, Florida

University of Pennsylvania Medical System, Philadelphia, Pennsylvania

Note that the list of facilities outlined above may change over time. Your/your child's physician will talk to you about which PBT facility you/your child should go to and you can help make the decision.



Do I have to pay to have my/my child's PBT in the U.S?

- You do not have to pay any of the ministry-approved medical costs for your/your child's PBT.
- You will have to pay for some or all of your/your child's non-medical costs.
 - Staff at the U.S. facility may help you find lodging and other local services. Some facilities may help arrange charity-supported lodging if it is available. See section F for additional information.

Here is a list of some of the things you may need to pay for:

- Travel costs (airfare and/or gas)
- Lodging and accommodation
- Local transportation
- Food
- Travel medical insurance for health problems that are not related to your/your child's PBT treatment
- Cell phone costs

Talk to your/your child's Ontario health care team to learn more about what you might have to pay for to get a better idea of costs and any assistance that may be available in the U.S.

Do/does I/my child have to get approval prior to going to the U.S. for my/my child's PBT?

- Yes. The MOHLTC has to give prior approval before you/your child can receive OHIP-funded PBT in the U.S.
- Your/your child's Ontario physician will submit an application to the MOHLTC on your/your child's behalf. More information about the MOHLTC's Out of Country Prior Approval Program can be found here: www.ontario.ca/outofcountry
- The MOHLTC processes applications for PBT in approximately 7 business days from the time that a complete application is submitted by your/your child's Ontario physician.
- You will receive a decision letter from the ministry, by courier, at your home. This letter is important so make sure you keep it safe.
- If approved for funding, any additional services (e.g. chemotherapy or additional surgery that was not part of the original plan) that you require must also receive prior approval from the MOHLTC. Obtaining approval for additional services is generally the responsibility of the PBT facility and your Ontario referring physician. You must let your Ontario referring physician know if the PBT facility



recommended additional services so your Ontario physician could request approval for funding from the MOHLTC.

- Services rendered in urgent circumstances in which it would be impossible, or so impractical, for the General Manager to be given notice before emergency services are rendered may be considered for funding by the ministry after the services have been rendered.

How quickly will PBT happen once I/my child get(s) the approval?

- You, your/your child’s physician and the U.S. PBT facility will work together to coordinate the timing of PBT services.

How much will my/my child’s Ontario health care team know about my/my child’s PBT?

- Your/your child’s Ontario physicians will be kept informed about how you/your child are/is doing at the U.S. facility.
- The U.S. facility will share all necessary details of your/your child’s care with your/your child’s Ontario physician so that they can take over care for you/your child once you/your child return(s) home to Ontario.

How long will I/my child be in the U.S.?

- You should plan to be in the U.S. for 4 to 8 weeks, depending on your/your child’s disease and treatment plan.
- Your/your child’s Ontario physicians and the U.S. team will be able to provide you with a better time estimate. How long you/your child have/has to stay may depend on various factors, which your/your child’s physicians will evaluate before and during your/your child’s treatment.

Information about what will happen during and after PBT treatment

- PBT is generally provided on an out-patient basis and you/your child will stay in a hotel, suite, a sponsoring charity or other lodging near the PBT facility.
- With PBT facilities that are specialized facilities, there may also be visits to affiliated hospitals for other forms of care.



- Your/your child's health care team will provide details for your situation.
- Some PBT facilities may provide local transportation necessary for scheduled medical visits.

Going home

- Once you/your child have/has completed PBT and your/your child's U.S. health care team thinks you/your child are/is ready to go home, you/your child can return home to Ontario.
- Your/your child's care will be transferred back to an Ontario hospital for follow-up.
- Your/your child's health care team in Ontario will contact you to tell you what will happen when you/your child come(s) back.



C. CHECKLIST FOR PATIENTS

(Note: For “Checklist for caregivers”, please refer to page 11.)

Passport and travel documents

If you/your child are/is a Canadian citizen:

- Check to make sure that your/your child’s Canadian passport is valid.
 - If you/your child do/does not have a passport or if it is out of date, you can ask for an urgent/emergency passport application at a Passport Canada office.
 - Call 1-800-567-6868 or visit www.cic.gc.ca/english/passport/ for more information.

If you/your child are/is a Permanent Resident of Canada

- Check to make sure that your/your child’s passport from your country of citizenship is valid.
- **Check to see if you/your child need(s) a visa to travel to the U.S.**
 - Citizens of some countries need a visa to travel to the U.S. Other countries are part of the Visa Waiver Program, which means citizens do not need a visa for U.S. travel.
 - Check the list of countries in the Visa Waiver Program here: <https://www.dhs.gov/visa-waiver-program-requirements>

For everyone

- If you have children under the age of 18 who will be crossing the border without both parents/guardians, make sure they have a written letter from both parents that gives permission for travel. Here is a sample letter for use: <https://travel.gc.ca/travelling/children/consent-letter>
- Bring your MOHLTC treatment approval letter with you. You may need to show the letter at the border.

Insurance

- **Services that have been prior approved are fully covered by OHIP and are paid directly to the PBT facility. So too are services required to treat complications arising from the provision of prior approved services.**



However, other health services that you may require while staying outside of Canada may not be covered by OHIP.

- For this reason you are strongly advised to purchase travel medical insurance if you do not have it through your workplace benefits. Whether you will rely on your workplace benefits, or you will purchase travel medical insurance, ensure that the coverage you/your child will receive is sufficient.
- Contact your insurance provider if you have Short-Term or Long-Term Disability through your workplace benefits. Tell them that:
 - You/your child have/has been approved by the MOHLTC to get PBT in the U.S.
 - You/your child will be traveling to the U.S. for your/your child's treatment and will be there for 4-8 weeks.
 - You can give them a copy of your approval letter if they need it.
- While it is not expected, you may want to ask about insurance products that can pay for costs in the unfortunate event that you/your child should die while in the U.S. These products are usually valid for life and may cover you/your child for vacations and business travel in the future. Some patients have found that this insurance gives them peace of mind. Ask your/your child's health care team if they know of a provider if you want to learn more.

Financial

- Call your bank and credit card companies to make sure they know you/your child will be traveling to the U.S. Do this so that they do not freeze your account when they see charges from the U.S.
- Ask your bank about fees to use bank machines in the U.S.
- If you get Employment Insurance (EI) Sickness Benefits, give Service Canada a copy of your approval letter from the MOHLTC so that you can keep getting your benefits while in the U.S. **Do this before you travel to the U.S.**
- Keep all of your receipts for travel, accommodation, food and other costs. You may be able to claim them as medical expenses on your next tax return to get a refund on part of the cost.
- Get some U.S. dollars before you travel, to pay for food and other costs while you are in the U.S.

Practical

- Depending on your/your child's situation, you may want to contact a lawyer to:



- Complete a Power of Attorney for Personal Care form (POA-PC) or request a POA-PC kit from your/your child's social worker. Bring your Power of Attorney forms to the U.S. facility. These forms tell your/your child's health care team who will make your decisions if you are not able to.
 - Update your will, if you need to.
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- Contact your cell phone provider and ask about travel packages. You may also have your cell phone unlocked and buy pay-as-you-go plans in the U.S.
 - Contact Canada Post to have your mail sent to your address in the U.S. or ask a family member or friend to collect your mail for you and tell you about bills that need to be paid.

Medication

- Speak to your/your child's physician about receiving a supply of medications for the duration of travel. Also confirm with your/your child's physician the best way to arrange additional supplies while outside of the country if necessary. Bring your/your child's medications in the bottles they came in.
- Get a letter from the physician who prescribed it about the need for the medication. You must tell border services about all medications you are bringing to the U.S.



Caregivers (Paediatric patients only)

Every child who goes to the U.S. for PBT must have an adult caregiver to help care for them.

Key points for caregivers:

- The caregiver must have authority to sign consent for the treatment, on behalf of the child, if the child does not have the capacity to consent.
- The caregiver does not have to be the same person the whole time. Friends and family members can take turns caring for the child.
- The caregiver must be physically strong and able to take care of the child. They must be able to help with things like dressing and bathing and giving medications. They will also be doing things like cooking, cleaning, shopping and laundry.
- The caregiver is expected to go with the child to all appointments and will be trained by facility staff to do things like dressing care and intravenous (IV) flushing.
- The caregiver must share lodging with the child but can sleep in a separate bed or bedroom.
- The caregivers should buy travel medical insurance in case they need medical care while in the U.S.



D. CHECKLIST FOR CAREGIVERS

Passport and travel documents

If you are a Canadian citizen:

- Check to make sure that your Canadian passport is valid.
 - If you do not have a passport or if it is out of date, you can ask for an urgent/emergency passport application at a Passport Canada office.
 - Call 1-800-567-6868 or visit www.cic.gc.ca/english/passport/ for more information.

If you are a Permanent Resident of Canada

- Check to make sure that your passport from your country of citizenship is valid.
- **Check to see if you need a visa to travel to the U.S.**
 - Citizens of some countries need a visa to travel to the U.S. Other countries are part of the Visa Waiver Program, which means citizens do not need a visa for U.S. travel.

Check the list of countries in the Visa Waiver Program here:

<https://www.dhs.gov/visa-waiver-program-requirements>

Insurance

- Buy travel medical insurance if you do not have it through your workplace benefits. Whether you will rely on your workplace benefits, or you will purchase travel medical insurance, ensure that the coverage you will receive is sufficient.

Financial

- Call your bank and credit card companies to make sure they know you will be traveling to the U.S. so that they do not freeze your account when they see U.S. charges.
- Ask your bank about fees to use bank machines in the U.S.
- Get some U.S. dollars before you travel to pay for food and other costs while you get settled in the U.S.

Medication

- Speak to your physician about receiving a supply of medications for the duration of travel. Also confirm with your physician the best way to arrange additional supplies while outside of the country, if necessary. Bring your medications in the bottles they came in.



- Get a letter from the physician who prescribed it about the need for the medication. You must tell border services about all medications you are bringing to the U.S.



E. IMPORTANT CONTACTS AND ADDITIONAL RESOURCES

Your/your child's health care team

Contact person at your/your child's Ontario hospital:

Contact person at your/your child's U.S. facility:

Health Care

Information about the MOHLTC's Out of Country Prior Approval Program:

www.ontario.ca/outofcountry

Travel documents

Find out if you need a visa to visit Canada: <http://www.cic.gc.ca/english/visit/visas.asp>

Information about the U.S. Visa Waiver Program: <https://www.dhs.gov/visa-waiver-program-requirements>

Information about getting an urgent Canadian passport application (not all passport offices process urgent applications): <http://www.cic.gc.ca/english/passport/times.asp>

Financial

Employment Insurance Sickness Benefits:

<https://www.canada.ca/en/services/benefits/ei/ei-sickness.html>



F. INFORMATION ABOUT HOUSING OPTIONS, SERVICES FOR INTERNATIONAL PATIENTS, CONTACTS, ETC, FOR ONTARIO PATIENTS AND THEIR FAMILIES WHO ARE CONSIDERING OUT-OF-COUNTRY PROTON BEAM THERAPY AS A TREATMENT OPTION

**Except for format changes this information is reproduced as it was provided to the ministry by the proton beam therapy facilities in response to a uniform questionnaire. The accuracy of this information is the responsibility of the facilities, which are listed here in alphabetic order.*

CINCINNATI CHILDREN’S HOSPITAL “Cincinnati Childrens” (preferred provider for pediatric patients only)

Location

Liberty Township, Ohio (outside of Cincinnati)

Main Webpage

<https://www.cincinnatichildrens.org/service/p/proton-therapy>

Advanced Treatment without Financial Barriers

At Cincinnati Children’s Proton Therapy Center we partner with our patients and families to ensure financial challenges aren’t an obstacle to receiving pencil-beam proton therapy treatment. We know the logistics for travel, housing and financial support can be overwhelming, but they don’t have to be with our support. That’s why we make the process as easy and comfortable possible.

With one call to our proton therapy intake coordinator, we can arrange and manage all aspects of your trip, including:

- *Housing:* we can help you to determine if a hotel, home rental, or Ronald McDonald house is best for your family.
- *Travel:* we will help you to determine the best way to travel from your home to our center.
- *Financial support:* we will work to secure available funding to defray travel and lodging expenses.

We provide these support services to parents and caregivers so they can focus on the patient’s and family’s medical and emotional needs instead of managing travel details.



Comfortable Suburban Location, Affordable Options

The Cincinnati Children's Proton Therapy Center is located just outside of Cincinnati in Liberty Township, Ohio. Our suburban location is ideally suited for international patient and family needs because it is safe, affordable, and easy-to-navigate with free on-site parking. In addition, you'll find a full-service grocery store, shopping, numerous restaurants, a theater and much more all within five minutes of the Proton Therapy Center.

Housing Options

The Cincinnati Children's Proton Therapy Center offers many discounted housing options including:

- *Hotels:*
Cincinnati Children's has affordable, discounted prices at several local hotels ranging from \$69USD - \$114USD per night for families receiving treatment at the Proton Therapy Center. Some of these hotels offer free transportation to and from the Proton Therapy Center.
- *Airbnb Home Rentals:*
Another cost-effective option is Airbnb home rentals. Several rentals are available near the Proton Therapy Center with rates ranging from \$650 - \$1,600USD per month.
- *Ronald McDonald House:*
The Proton Therapy Center is halfway between two Ronald McDonald Houses, which lodges out-of-town families and patients for free and on many nights donated meals are available to those staying without cost. Please note, there is a recommended donation of \$15-25USD per night, but patients are not turned away due to an inability to pay. Visit these websites for more details about our local Ronald McDonald Houses:
 - <http://www.rmhcdayton.org/>
 - <https://www.rmhcincinnati.org/>
- *Proton Therapy Apartments:*
The Bold and Brave Kids Foundation has generously secured two fully-furnished, two-bedroom apartments specifically for our out-of-town proton therapy patients and their families located within one mile of the center. These are allocated on a first come first serve basis by the Foundation and some of the time patients start off with another housing option, but move in early during their treatment time.



As previously mentioned, our Proton Therapy team is here to help you determine which housing option best serves your family's needs. Please find contact information below.

Traveling to Cincinnati

Liberty Township, Ohio is 850km from Toronto, Ontario and is therefore an accessible one-day drive by car for most Ontario residents.

In addition, there are several direct flights daily from Toronto Pearson International Airport (YYZ) to the Cincinnati/Northern Kentucky International Airport (CVG). If a patient/family is flying to Cincinnati, complimentary transportation is offered from the airport to lodging and the Proton Therapy Center.

Our staff works closely with families to consolidate appointments on Fridays and Mondays to allow for weekend travel back home when possible.

Financial Assistance

Cincinnati Children's and our Proton Therapy Center partner with dozens of charitable foundations to provide financial assistance to our patients. Some of the most commonly-used resources are:

- Ronald McDonald House
- Alex's Lemonade Stand
- Brave and Bold Kids Foundation
- Compass to Care
- Champions Do Overcome
- Vivian's Victory
- plus dozens more

Our intake coordinator will assess your family's needs and navigate the network of charitable foundations in order to secure the necessary financial support.

In addition to charitable foundation support, all proton therapy patients receive a welcome bag from our charity partner, Free Throw for Kids, which includes gas cards, cafeteria cards and several restaurant cards.

An Experienced, Dedicated Team to Serve International Patients

Cincinnati Children's serves patients from more than 100 countries. Last year, our oncology team treated patients from 18 countries and 42 states. Several departments within Cincinnati Children's work together, behind-the-scenes to seamlessly serve to our international patients – the Proton Therapy Center staff, Concierge Services, International Patient Program and Destination Excellence.



Proton Therapy Center Staff

Every patient traveling from Ontario to our Proton Therapy Center will have a dedicated proton nurse coordinator and child life specialist, who work closely together to insure our patients' clinical and non-clinical needs are met while receiving treatment at Cincinnati Children's. For instance, our Proton Therapy Center offers on-site education support to maintain schooling and educational priorities while in Cincinnati for treatment.

Before arriving to Cincinnati, our proton therapy intake coordinator works with each patient to arrange accommodations and secure the appropriate foundation financial support for travel and housing as previously described.

After you arrive, we will continue to provide dedicated support and service. Upon arrival, our proton nurse coordinator will provide a comprehensive orientation during your first clinic appointment. Then, nurse coordinator and our social worker will be your main points of contact and will provide professional and personalized care designed specifically to your unique needs. For patients and families who prefer to communicate in a language other than English, we have an extensive translation services department to help with necessary translations from any language. The Proton Therapy Center staff will ensure an interpreter is present for the services and visits where a live interpreter is needed.

Concierge Services

Your intake coordinator will work with the Cincinnati Children's Concierge Services team to make a patient/family's time as stress free and comfortable as possible. This includes the logistics with travel arrangements and other patient/family needs while receiving treatment such as locating nearby places of worship, grocery stores, laundry/dry cleaning, banking and other personal concierge services. Concierge Services also offers free or discounted tickets to activities all over Cincinnati for patients and their families while in town.

International Patient Program and Destination Excellence

Our International Patient Program and Destination Excellence teams have extensive experience helping international families manage the challenges of living abroad for an extended period of time and understand the unique needs of our international patients and families. These teams partner with the Proton Therapy Center staff to make the experience of patients, families and their referring physicians as easy and comfortable as possible.



About Cincinnati Children's

Proton Therapy Center

Our Proton Therapy Center is one of only two such centers in the world owned by a children's hospital. Our center was designed and built for the pediatric patient with a bright and colorful environment where our team of cancer specialists is dedicated making each family's experience as relaxed and comfortable as possible.

Our staff, with more than 70 years' combined proton experience, utilize the most advanced technology that offers the most precise and advanced form of radiation therapy available in the world today to all our patients. This specialized pencil beam technology destroys cancer cells while minimizing damage to surrounding healthy tissues and organs. As a result, patients experience fewer short-term side effects and long-term complications than with traditional radiation therapy. This is especially important for children, whose bodies are still growing and developing.

The Cincinnati Children's Proton Therapy Center is located at our Liberty Campus. On-site services at this hospital include a medical oncology clinic, pharmacy, imaging center, laboratory testing, central line care, emergency department, child life services and the only accredited pediatric cancer rehabilitation program in the world.

Liberty Campus

Our Liberty campus is equipped to administer proton therapy, as well as inpatient and outpatient oncology services, at the same location. Since all care can be administered in one place, families do not need to travel via ambulance, or otherwise, to receive necessary, additional services.

Altogether, the services and experience offered at the Cincinnati Children's Proton Therapy Centers – from our proton expertise, experience serving international patients, affordable suburban location, full-service hospital and holistic approach to both clinical and whole-family needs during stays – makes our center a great choice for patients and families from Ontario.

Contact Information for Patients, Families, Social Workers

Proton Therapy Team

Cincinnati Children's Proton Therapy Center

Phone: +1 513.636.ATOM (2866)

Email: proton-therapy@cchmc.org.



Proton Therapy Center Intake Coordinator

Holly Hagerman

Phone: +1 513.517.0399

Email: Holly.Hagerman@cchmc.org

Proton Therapy Center Nurse Coordinator

Mary Beth Morgan

Phone: +1 513.517.0392

Email: Mary.Morgan@cchmc.org

MASSACHUSETTS GENERAL HOSPITAL “Mass General” (preferred provider for pediatric patients only)

Location

Boston, Massachusetts

Main Webpage

<https://www.massgeneral.org/children/services/treatmentprograms.aspx?id=1624>

Recommended Pediatric Housing Options

We have a close relationship with several facilities in the area that offer discounted rates to patients and their families that come to Massachusetts General Hospital for extended stay treatments. We always encourage patients to apply for housing at these institutions as soon as they have treatment dates confirmed as there can be limited availability, and they may be placed on a wait list. Please see below for further information.

Ronald McDonald House at Boston Harbor – No fee

(Formerly Home Away Boston)

617-398-6458

250 1st Ave, Boston, MA,

2.2 miles from Mass General Free parking. Free shuttle.

Private apartments for families of pediatric patients who live at least 40 miles from Mass General.

Application available online at www.rmhbostonharbor.org/

Christopher’s Haven – \$30/night

857-233-4178

One Emerson Place, Suite 2N, Boston, MA



Adjacent to Mass General

For those receiving a minimum of 4-6 weeks outpatient pediatric cancer treatment. Primary Caregiver must be at least 18 and able to communicate in English.

Contact Catie Botting, Family Services Manager

catiebotting@christophershaven.org <http://christophershaven.org/>

MGH at the Beacon House – \$69-\$118 per night

19 Myrtle Street, Boston MA (5 blocks from MGH)

617-726-7679

Small studio accommodations with private bathroom and kitchen

MGH-affiliated facility

No on-site parking; parking available at MGH garages

Additional housing resources

Additional resources for adult and pediatric housing can be found at our MGH

Social Services webpage <http://www.mghsocialwork.org/accommodations-list.pdf>

. This page provides an overnight accommodations list that we provide to families during the patient intake process.

If at any time, the families need assistance during the application process, our Proton Access Manager, Lisa Neal (LPNeal@partners.org) is always available as well as our Guest Services group within our International Patient Center.

Transportation

Our guest services specialist through our international office is available to help provide complimentary shuttle transportation patients flying into Logan Airport in Boston. This transportation will take them from the airport to their place of stay.

Financial Resources

Our licensed social worker is always available to aide in researching any additional and financial resources that are available to assist with housing or expenses while here.

Services for International Patients

We understand that relocating to an unfamiliar city for treatment can be stressful. While the proton treatment course, if outpatient, can take a few hours each weekday to complete throughout typically 6- 8 weeks, it still leaves some time for patients and families to fill their time while they are here, if they desire and are able to. Our facility has an all hands-on deck approach to making sure families are as comfortable as possible while here during their stay. When they arrive,



families will have an introductory appointment at the international patient center (<https://www.massgeneral.org/international/>) where they are provided a welcome packet that provides key information about accessing the resources available to them. Families are assigned an international patient liaison that serves as a main point of contact if they need anything during their stay. Through that office, a guest service steam member is also available to help with any questions regarding lodging, dining, and tourism activities. They can also provide guidance to the best areas for shopping for necessity items such as groceries, toiletries or clothing while here. On our hospital webpage, the proton therapy center has an area to view local Boston Area information as well as providing building maps and local hospital campus maps. Patients are welcome to visit our 'Visiting Boston' page before their arrival to start planning things for the family to do while here during their extended stay: <https://www.massgeneral.org/visit/boston/>. This webpage provides local area transportation information as well as local area hotels and city attractions.

Contact information of staff assigned to assist international patients or their social workers with non-clinical questions about Massachusetts General Hospital and Boston

International Patient Center and Guest Services:

Canadian Patient Liaisons: Anne Marie Blondin (ablondin@partners.org) and Max Perez (mperez41@mg.harvard.edu)
 Phone: 1.617.726.2787

Pediatric Clinical Coordinator, Proton Therapy Center:

Elizabeth Mullin (emullin@mg.harvard.edu)
 Phone: 1.617.724.1836

Proton Access Manager, Proton Therapy Center:

Lisa Neal, R.T.(T) (lpneal@partners.org)
 Phone: 1.617.724.0661

Additional Information

Our Francis H Burr Proton Therapy Center has been in operation since 2001. Since then, thousands of adults and children have received highly customized, team-based treatment here, with advances in imaging and technologies making proton beam therapy ever more precise. We encourage patients to visit our website to watch some informative videos on the simulation and treatment process.



MGH Radiation Oncology Proton website:

<https://www.massgeneral.org/radiationoncology/BurrProtonCenter.aspx>

Treatment Simulation Process:

<https://www.massgeneral.org/radiationoncology/patientsandfamilies/virtualguides.aspx>

Patient Experience Video:

<https://www.massgeneral.org/radiationoncology/news/multimedia.aspx?id=625>

We find these videos to be a useful tool in providing patients a view into the patient experience prior to their arrival. This information allows them to begin to think of questions they may want to ask at the time of their consultation appointment.

General Support / Supportive Care:

We believe that the overall patient experience is incredibly important. We have team members available throughout the patient’s stay that can help no matter the issue.

- o Radiation Oncologist
- o Nurse Practitioner / Nurses
- o Radiation Therapists o Child Life Specialist
- o Licensed Social Worker
- o International Patient Liaison
- o Guest Services Specialist
- o Proton Access Manager

In addition, while under treatment we have a multitude of supportive care services available to all radiation oncology patients at no charge.

- o Art Therapy
- o Floral Therapy
- o Gentle Yoga
- o Integrative Therapies
- o Massage Therapy
- o Music Therapy
- o Spiritual Wellbeing Sessions
- o Toy and Sibling Programs*

(*Toy Friday is an anticipated day for all the children under treatment. The toys are reward for a “job well done” during



that week. Siblings are also acknowledged and share in the fun of selecting a toy from the Treasure Cabinet each week.)

While supplies are available, we also are able to provide tickets to families for local activities such as Museum of Science, Boston Aquarium, Duck Boat Tours, and more. All of these activities are intended to provide community building and memory-making opportunities for families.

NORTHWESTERN MEDICINE CHICAGO PROTON CENTER (preferred provider for adult and paediatric patients)

Location

Warrenville, Illinois (outside Chicago)

Main Webpage

<https://www.chicagoprotoncenter.com/>

Patient Services Team

If you are traveling to Northwestern Medicine Chicago Proton Center (Chicago Proton Center) in Warrenville, Illinois, for proton therapy treatment, our Patient Services Team will help ensure that you feel at home during your stay in the area. The team can help arrange for accommodations, and suggest options for transportation, restaurants, sports and entertainment. We can also assist you in finding local resources such as pharmacies and places of worship. If you need directions, additional help or more information, we are available to support you Monday through Friday during Chicago Proton Center hours. The Patient Services Team is available at 630.821.6461.

- Lodging

- Pediatrics: Pediatric patients and families can stay free of charge at the Ronald McDonald House located near NM Chicago Proton Center. Lodging arrangements will be coordinated by Proton Center patient services staff
- Adults: Adult patients and families can stay at one of a number of local hotels with which NM has negotiated discounted rates. For a partial listing see <https://www.chicagoprotoncenter.com/explore-the-center/out-of->



town-patients/hotels-housing. For a complete listing contact the Patient Care Services Team at 630.821.6461. Please note that lodging will be at the patient's expense.

- Transportation
 - Pediatrics: Transportation to and from the Ronald McDonald House will be arranged by local staff and offered free of charge.
 - Adults: Patients staying at local hotels can access free hotel shuttles transporting patients to/from treatment.
 - Other: Patients should plan to arrange for transportation from the airport to their lodging destination. Patient Services staff can help patients and families secure rental cars should that be a more convenient option. This would be at the patient's expense. Uber and Lyft are available for other local travel as needed.

- Meals
 - Pediatrics: Patients and families at the Ronald McDonald House will be provided two meals per day.
 - Adults: Local hotels offer complimentary continental breakfasts and can arrange for grocery delivery service at the patient's expense (if desired).
 - Other: Proton Center patient services staff can provide information about local restaurants and or grocery stores as needed.

- Contact Information for Social Worker and Child-life Specialist
 - Social worker support with emotional support, education/tutoring, other needs. Rebecca Ness, MS, MSW, LCSW, 630-315-1875, rness@livingwellcrc.org.
 - Child-life Specialists for pediatric patients. Aileen Maxwell, MS, CCLS, 630-821-6441, aileen.maxwell@nm.org.

- Other Support Services
 - LivingWell Cancer Resource Center offers support groups, classes.



- *Your Guide to Suburban Chicago* (information on dining, entertainment, worship, pharmacy, daily needs) is available from the Patient Care Services Team at 630.821.6461.

UNIVERSITY OF FLORIDA HEALTH PROTON THERAPY INSTITUTE “UF Health Proton Therapy Institute”

(preferred provider for adult and pediatric patients)

Location

Jacksonville, Florida

Main Webpage for Patients and Families

<https://www.floridaproton.org/patients-families>

Lodging

Ronald McDonald House - <https://rmhcjacksonville.org/>

The RMH is conveniently located near Jacksonville’s top pediatric healthcare providers. Situated near the beautiful St. John’s River and less than 5 minutes away from Downtown, San Marco is a vibrant, historic community filled with popular restaurants, boutiques and entertainment options perfect for the entire family.

Staying in Jacksonville <https://www.floridaproton.org/patients-families/staying-in-jacksonville>

In this local housing guide, we have identified apartments, condos, houses, hotels, and other accommodations that provide comfortable residences for our patients. The housing options included are listed by their location and convenience to the UF Health Proton Therapy Institute. While there are many other places for you to stay in Jacksonville, we recommend that you first explore availability of accommodations listed here since most have special rates and amenities for our patients.

Note



Please note that we do not arrange housing. This list is merely a guide which we hope you will find useful to locate a suitable place to stay. Please contact the proprietors directly and always tell them you will be treated at the UF Health Proton Therapy Institute to ensure the best rate. Although we do our best to make sure our current housing information is up-to-date, please note that prices and listing availability are subject to change, and we recommend that you get a written lease. Thank you!

Transportation

- Transportation to and from medical appointments through UF Health Proton Therapy Institute van program.
- For detailed information on transportation options in Jacksonville, please visit the following webpage:
<https://www.floridaproton.org/patients-families/transportation>

Social Worker Contact Information

Heather Oakley, LCSW, OSW-C
 Director of Social Services & Clinical Social Worker
hoakley@floridaproton.org
 Office: 904-588-1293
 Cell: 904-239-0540

Patient Services

- Full-time licensed clinical pediatric oncology social worker
- Full-time certified child life specialist
- Full-time artist-in-residence
- Bi-weekly Family Fun Night provided for pediatric patients and families. Dinner and community entertainment/activities provided on-site to all pediatric patients and families
- Pediatric support group facilitated by clinical social worker which is held concurrently with separate art activity for patients/siblings
- Lists of cultural, spiritual and dietary resources for specific populations
- Patient Loan Closet with items that families may borrow such as car seats, strollers, toys, cooking utensils, etc.
- International patients are provided with complimentary US cell phone and GPS for use while they are staying in Jacksonville
- Wednesday patient lunch offered each week to encourage peer support and to provide education



- Music Night (first Tuesday of the month) – local musical entertainment provided with refreshments
- Weekly Patient/Caregiver Yoga
- Adolescent and Young Adult psychosocial group outings
- Adolescent and Young Adult peer support and educational programming through the Nemours Children’s Specialty Clinic CHAT program and the Live for Today program (<https://www.live-for-today.org/>)
- Discounts membership to local YMCAs
- Complimentary Admission to local attractions:
 - Jacksonville Zoo and Gardens: <http://www.jacksonvillezoo.org/>
 - Museum of Science and History: <https://themosh.org/>
 - Cummer Museum of Art & Gardens: <https://www.cummuseum.org/>
 - Ripley’s Believe It or Not!: <https://www.ripleys.com/staugustine/>
 - The Catty Shack Ranch Wildlife Sanctuary: <https://cattyshack.org/>

Other Information about UF Health Proton Therapy Institute

- We have treated more children than any other facility in the world and offer a proven record of success. Our outcomes are regularly assessed for quality assurance and shared in publication.
- The University of Florida is one of the oldest and largest academic medical centers in the southeastern United States. In addition to clinical care, our mission spans research and education. This atmosphere of innovation and inquiry ensures the most advanced treatment options are available to our patients.
- As 90% of our pediatric patients come from outside Jacksonville, we recognize the unique obstacles confronting families who are distant from their local communities during a stressful time. We have always focused on supporting not only patients, but also their siblings and parents. Our success in this endeavor and much more is reflected in exit interviews where pediatric patient satisfaction is 100%.
- Jacksonville offers a favorable climate, with temperate winters and warm summers. The beach and St. Johns River are easily accessible and provide relief during the hotter months of the year.
- Jacksonville is close to the Orlando area which is full of age-appropriate diversions for pediatric patients and their families (Disney, Universal, SeaWorld, Aquatica and Legoland Florida, Kennedy Space Center).



UNIVERSITY OF PENNSYLVANIA HEALTH SYSTEM “PENN MEDICINE” (preferred provider for adult patients only)

Location

Philadelphia, Pennsylvania

Main Webpage

<https://www.penncare.org/cancer/navigating-cancer-care/programs-and-centers/roberts-proton-therapy-center>

Accommodations (note that the social worker should be contacted first for any necessary

Referrals – see below for contact information)

- Airbnb
www.airbnb.com
1-855-424-7262 (many languages available)
- Airbnb’s OPEN Homes Medical Stays
openhomes@bonemarrow.org
Program provides free temporary housing to cancer/transplant patients and caregivers while receiving lifesaving treatments. Any patient who lives at least 30 miles away from his/ her treatment facility is welcome to apply. Phone number: 1-800-365-1336
- American Cancer Society Hope Lodge
<https://www.cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge/philadelphia.html>
The Hope Lodge is a free lodging facility for patients and their caregiver. It is located in Cheltenham, PA approximately 13.5 miles north of the Penn Medicine campus. Phone number: 267-622-6000.
- American Cancer Society Hotel Partners Program
<https://www.cancer.org/treatment/support-programs-and-services/patient-lodging/hotel-partners.html>
Through a generous nationwide partnership with Extended Stay America®, the American Cancer Society will offer free or reduced rate lodging in cities with Extended Stay hotels for those who qualify for the program. Phone number: 1-800-227-2345.

*Cancer Support Community Airbnb Partnership Program

<http://www.cancersupportcommunity.org/>

The Airbnb community will provide free housing for patients and caregivers who travel at least 100 miles for treatment, scans, clinical trials



and other medically necessary care. Airbnb specific line of our CancerSupportHelpline (877-793-0498) Helpline open 9AM-9PM.

- Hosts for Hospitals
www.hostsforhospitals.org
 Hosts for Hospitals provides low-cost lodging and support at volunteer-host homes as a caring response to the housing needs of patients and their families who come to the Greater Philadelphia area for medical care. The cost per family is \$20 per night for the first 14 nights and \$10 per night thereafter. Accommodations vary from host to host. Guests share household facilities with host families and are matched with host-homes chosen to meet each guest family's specific lodging needs. All homes have been visited by Hosts for Hospitals program staff to ensure safety and comfort. Phone number: 484-380-2999. Email: lodging@hostsforhospitals.org. Website: www.hostsforhospitals.org. An easy online application may be submitted from this webpage.

- Nick's House
<https://headstrong.org/our-services/nicks-house/>
 Nick's House provides complimentary lodging for out-of-town patients and their families who are undergoing cancer-related treatment in the Philadelphia metropolitan area. Nick's House is not a medical facility but a guest house designed to meet the unique needs of patients, their families and/or caregivers. For more information, please contact: 610-461-5987.

- 3737 Chestnut
www.Korman3737.com
 LIVE KORMAN residential Fully Furnished apartments in University City
 Phone number: 215-240-6803

- UrHomeInPhilly
<https://urhomeinphilly.com/>
 Locations in Rittenhouse Square and University City. Distance from Hospital: 0.6-1.8 miles. Parking: Garage Parking Available. Amenities: Apartments ranging from 1-3 bedrooms, handicap accessible, smoke-free, in-home laundry, full kitchens, shuttle service, fitness rooms. Each location has additional amenities specific to that location. Phone number: 1-800-913-9484.

- Other



Penn Medicine has negotiated short term and long term rates with many preferred providers. For further information, contact Penn Global Medicine International Office (see below). Homewood Suites, Hilton University City, offers free shuttle to and from Hospital of the University of Pa, from 6am-9:30 PM Monday through Friday.

Quality of Life Programs

Penn Radiation Oncology is pleased to offer patients and their caregivers full access to our Quality of Life Programs. These integrative oncology programs are designed to support patients and caregiver throughout their cancer treatment journey by offering activities that promote wellness and healing such as yoga, art therapy, pet therapy, exercise and more. Our team of integrative oncology practitioners work with each patient and caregiver to help design a program that meets their individual needs and interests. We are happy to offer these programs to encourage patient engagement to provide support and cultivate interest in the healing arts during the course of radiation treatment. All programs take place in our brand new studio, located within our waiting room so that it is convenient for patients and caregivers to access. The Quality of Life Programs are dedicated to encouraging the overall health and wellbeing of our patients and caregivers and are offered daily. For further information, including a current schedule of activities, please email

RadOncPatientEngagement@uphs.upenn.edu

Contacts for Patients, Families and Social Workers in need of Information

Penn Global Medicine International Office:

- Naysha Soto: Naysha.Soto@pennmedicine.upenn.edu 215-615-0441
- Zainab Alsawaf Zainab.Alsawaf@pennmedicine.upenn.edu 215-662-7640
- Ubah Ahmed: Ubah.Ahmed@pennmedicine.upenn.edu 215-614-0450

Penn Global Medicine international care coordinators help arrange logistics of treatment and assist with providing Complimentary Meal Vouchers as part of our international patient program.

Social Workers Group:

- Brittany Fols: Brittany.Fols@pennmedicine.upenn.edu 215-220-9630
- Lauren Burling: Lauren.Burling@pennmedicine.upenn.edu 215-615-5080



- Nicole Ellis: Nicole.Ellis@pennmedicine.upenn.edu 215-615-5603
- Tracy Lautenbach-Hynes:
Tracy.LautenbachHynes@pennmedicine.upenn.edu
215-662-6193
- Neal Niznan: Neal.Niznan2@pennmedicine.upenn.edu 215-349-8183