

Proton Therapy

Guide to your care

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Fred Hutch is an independent, nonprofit organization that also serves as the cancer program for UW Medicine. Together we provide you with the specialized focus of a top-ranked cancer center and the comprehensive services of a leading integrated health system. You'll also have access to the latest research, treatment options and clinical trials.

UW Medicine



Welcome to Fred Hutch Cancer Center - Proton Therapy. Thank you for placing your trust in us. We are devoted to giving you the best possible care and support throughout your time here.

We understand that choosing a cancer treatment can be overwhelming. We created this guide to help answer questions you might have. Please read it, keep it as a reference, and feel free to share it with your caregivers, family and friends.

When you seek treatment at Fred Hutch, you access a network of providers whose sole mission is the pursuit of better, richer lives for our patients. Your health, safety and comfort are our highest priorities.

If you have any questions please contact us at (206) 306-2800 or **Info.Proton@fredhutch.org**.

Warmly,

a. Shephil

Annemarie Shepherd, MD Medical Director

What is proton therapy?

Proton therapy is a type of radiation therapy that uses beams of protons (tiny particles with a positive charge) to kill tumor cells. This type of treatment can reduce the amount of radiation damage to healthy tissue surrounding a tumor.

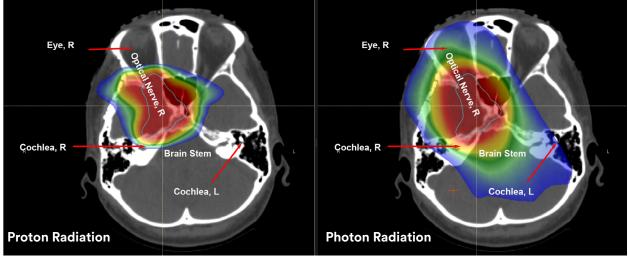
Studies have shown proton therapy can help treat a broad range of tumors, including those of the brain, central nervous system, gastrointestinal tract, head and neck, breast, lung and prostate, as well as sarcomas (tumors in the bones and soft tissues).

Because it can be so precisely targeted, proton radiation is especially useful for childhood cancers, where the impact of excess radiation can cause long-term damage.

Proton beam radiation is different than standard X-ray radiation (photon radiation)

The biggest difference between proton therapy and standard (photon) radiation is that standard radiation does not stop at the edge of the tumor, but continues into healthy tissue surrounding the tumor. This can cause damage to nearby healthy tissues.

Proton radiation delivers a beam of protons that stops at the tumor, which can reduce the amount of radiation delivered to healthy tissue. Research shows proton therapy can minimize short- and long-term side effects, reduce the occurrence of secondary tumors and improve patients' quality of life.



These MRI images show the brain receiving radiation (colored areas).

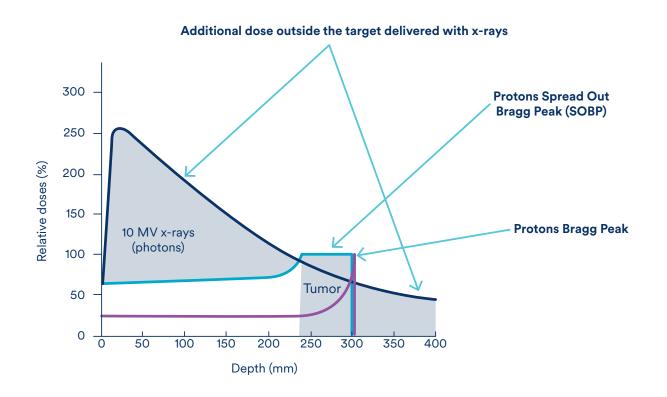
The illustration shows the difference between proton therapy on the left, where less healthy tissue is subjected to radiation, and standard X-ray radiation on the right, where more radiation affects surrounding, healthy tissue.





What can I expect with proton therapy?

Proton therapy is safe, noninvasive and painless for most patients. It does not require an overnight stay in the hospital. Treatments are usually administered five days a week, for a period of one to nine weeks. The total number of treatments needed depends on the location and size of the tumor. Daily treatment sessions may last up to 30 minutes. Most of that time is spent making sure you're in the right position for treatment. The radiation therapy typically lasts just a few minutes.



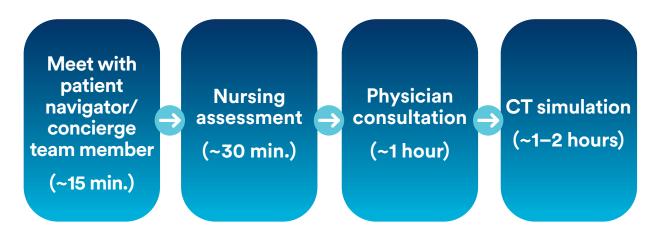
A closer look at the science behind proton therapy

Protons are heavy charged particles that can be manipulated to release their energy at a precise point. The more energy, the deeper the protons can penetrate the body. The amount of proton energy is calculated to release the proton radiation precisely at the tumor site. As they travel through the body, protons release only a small amount of radiation until they suddenly peak. The physician and care team can calculate the exact point of the peak (called the Bragg Peak, named after William Henry Bragg, who discovered it in 1903) which is designed to conform to the shape of the tumor. Immediately after that point, the radiation dose falls to zero.

You can find information on disease-specific conditions and proton therapy, as well as many disease-specific resources, at **FredHutch.org/ProtonTherapy.**

What to expect before treatment

Your first day at Fred Hutch - Proton Therapy (expected time is 3–4 hours)



Between CT Simulation and your first treatment (2–3 weeks)

CT simulation is used to create your treatment plan Treatment plan goes through a series of steps to make sure it is accurate

Scheduling receives treatment plan, then calls you with schedule

Arrive for your first day of treatment

Please note: You may have additional appointments at Fred Hutch or UW Medicine before you start treatment such as blood work, magnetic resonance imaging (MRI) or positron emission tomography (PET) scans. Your patient care coordinator may be able to help you schedule any additional tests. If you have any questions during this time, or if you haven't received any updates, please contact our patient care coordinator team at (206) 306-2800 or Access.Proton@fredhutch.org.

Your consult

During your first consult at the proton therapy facility, you will meet with your doctor and nurse. They are members of your personal care team, which also includes the radiation therapists. Your personal care team will treat and support you throughout the course of treatment at Fred Hutch, and will remain involved in your follow-up care (see page 14 for a list of care team members).

Your computed tomography (CT) simulation

After your consult and any additional tests, you will have a computed tomography (CT) simulation scan at the proton facility. This will take up to two hours, including preparation time. During this time, your nurse will explain the treatment process and give you time to ask questions.

The purpose of this scan is to gather images of your tumor and normal tissue from many angles so your doctor and dosimetrists can plan your specific treatment and make sure you are positioned correctly in the machine during your upcoming proton therapy. To help with positioning, they may use special immobilization devices such as masks, leg molds, head rests, sponges, and pillows that are customized for your body.

Depending on the location of your tumor, you may receive a contrast agent, or dye, before your CT scan so the tumor is easier to see. The dye may be injected through an intravenous (IV) line, taken orally (by mouth) or given through a catheter.

Our patient navigator/concierge team will take your photo to create an ID badge. When you arrive for treatment, we will give you your badge and notify your treatment team that you are ready for your appointment.

Getting your treatment plan

About 2–3 weeks after your CT simulation, your scheduler will call you to review the treatment schedule prepared for you.

Most patients have therapy five days a week (excluding weekends and holidays) for one to nine weeks, depending on the total number needed.

A number of factors impact scheduling, including the time required to set up equipment, the need to prioritize morning appointments for pediatric patients who can't eat or drink before treatment, and staffing levels. Because of this, you will likely be offered only one or two appointment times for each visit. We will do our best to accommodate you, but please know that due to these complexities, available appointment times are limited.

What to expect during treatment

During your treatment sessions

When you arrive for your treatment, you'll check in at the front desk, we will hand you your badge and notify your care team that you are ready for your appointment. After you're checked in, you may relax in the lobby until you're called for your appointment. To prepare for treatment, you may be asked to change out of street clothes into a gown. There are secure lockers for you to store your clothing or other personal belongings.

Once ready for treatment, you will be walked to the treatment room where you will lie on a treatment bed or sit in a treatment chair, and your radiation therapists will position your immobilization devices properly. You will be automatically moved into position before each treatment using a robotic positioning system.

During the actual treatment, you will not feel or see the proton beam. You may hear some clicking from the equipment around you, but after a few treatment sessions patients typically stop noticing the sound. Your radiation therapists will need to leave the room when the beam is active, but they will watch you through a video monitor nearby and can easily talk to you.

The entire session will take about 30 minutes. No recovery time is needed, and you may immediately return to your normal daily activities.

QA Scans

At times throughout your treatment, your attending doctor may order a Quality Assurance Scan (QA scan). This will typically be added just before or after your daily treatment based on the availability of the CT machine. The QA scan is compared to your original CT scan to ensure that the current treatment plan is still performing as expected. It is common for the QA scan to show slight changes in the plan or anatomy, in which case the doctor will adjust the treatment plan as needed.

On treatment visits (OTVs) with your care team

Once a week you will have a meeting, called an On Treatment Visit (OTV), with a nurse and radiation oncologist to discuss how your therapy is going. This is a good time to ask any questions you may have. In some cases, your doctor may order additional tests such as blood tests, CTs, MRIs or other scans. We do our best to schedule your OTVs around treatment sessions, so there is no need to make an extra trip to Fred Hutch.

What to expect after treatment

Patient graduation

We celebrate each patient's final treatment with a graduation ceremony. Patients receive a diploma and a challenge coin, and can also choose to ring the bell in the lobby to celebrate!

After treatment is complete

Your radiation oncologist will work with you to create a follow-up plan for your care. Typically, your first follow up appointment will be 3–4 months after treatment is complete. If you will be following up at our proton therapy facility, a member of our patient care coordinator team will contact you to schedule your visit and help you coordinate any lab draws or scans you may need prior to your follow up appointment.



Insurance coverage information

Your patient care coordinator, who is also a financial counselor, will help you understand your insurance benefits and provide you an estimate of your cost responsibility for proton radiation therapy before your first treatment.

Many U.S. insurance providers, including Medicare and many state Medicaid programs, cover proton therapy treatments.

Before your first consultation, your patient care coordinator will confirm your benefits and coverage. We will also find out if your insurance provider requires authorization for treatment. If it does, we will request it after your doctor confirms you are a candidate for proton therapy. Please note that authorization can take up to two weeks.

After your insurance carrier makes a decision, your patient care coordinator will contact you to discuss next steps. You can check in with them to find out the status of the request at any time; however, we will contact you once we have received the decision.



The Gantry treatment room at the Fred Hutch proton therapy facility

Patient services overview

During your treatment, our patient navigator/concierge team is here to help with patient services and non-medical needs. They are available Monday through Friday, 7:00 a.m. to 5:00 p.m. via **Concierge.Proton@fredhutch.org** or **(206) 306-2028.**

Our team's goal is to make your time here as stress-free and comfortable as possible.

They can connect you with:

- Places to stay, transportation, directions, and activities
- Networking opportunities for you and your family
- Support groups and programs (see page 12 for details)
- Child-life specialists, who help children undergoing treatment understand the treatment process and offer emotional support and more. Learn more at **FredHutch.org/pediatric-proton-therapy.**
- Patient care coordinators, who can help with any questions about your insurance or other financial needs

Other patient services available at our proton therapy facility include:

- Free parking once treatment begins
- Comfortable gowns and robes for patients with cancer sites below the neck
- Soothing, welcoming lobby
- Free beverage and snack bar
- Free Wi-Fi access
 Network: Guest-PPTC
 Password: Protons4U



Connecting with other patients

Many of our patients find comfort in connecting with other patients and families. Below are some of the ways we help people come together.

Patient advocates

Patient advocates are people who have been treated with proton therapy at Fred Hutch and are eager to offer their support and share their stories. If you'd like to talk to a patient advocate, please let our patient navigator/concierge team know. When you have completed treatment, you will have the opportunity to become a patient advocate yourself.

Virtual support groups

We offer two monthly support groups that are open to prospective, current, and former patients and caregivers. The Prostate Cancer Support Group shares resources about proton therapy and provides a space for discussion about prostate cancer and treatment. The Guided Meditation group helps manage stress and promote wellbeing through meditation practices. Each of these groups meet virtually. If you would like to participate, please ask the patient navigator/concierge team for details.

Facebook and Facebook support group

Fred Hutch - Proton Therapy has a public Facebook page (**facebook.com/ fredhutchprotontherapy**) that shares updates about the facility, wellness information, industry news and more. Fred Hutch also has a private Facebook group, which is available to patients who are undergoing or have undergone treatment. This closed group is a place for patients to share information or updates with other patients, ask questions or to get to know each other. Please ask the patient navigator/concierge team for the links to our Facebook pages.

Read our newsletter

Each month we produce an e-newsletter with provider profiles, news from our proton facility, nutrition information, patient stories, and more. Ask the Patient Navigator/ Concierge team to add you to the mailing list; scan this QR code or visit the link below to sign up for the newsletter. **bit.ly/protonnewsletter**

Your care team



Annemarie Shepherd, MD, Medical Director

Dr. Shepherd is a board-certified radiation oncologist who specializes in treating lung cancer, mesothelioma and thymic tumors.

She is an Associate professor of Radiation Oncology at the University of Washington School of Medicine. Dr. Shepherd helps develop clinical and research initiatives exploring the application of proton therapy in cancer therapy with a focus on lung cancer, thymic tumors and understanding radiationrelated toxicity and patients with inherent sensitivity to radiation.

She has published extensively and written, administered and led multiple clinical trials.

Dr. Shepherd earned her medical degree at Rutgers Robert Wood Johnson Medical School, and completed her residency in radiation oncology at the University of Pennsylvania.

Your radiation oncologists

Your radiation oncologist is the leader of your personal care team at Fred Hutch and will manage your care with the support of other highly-skilled medical professionals trained in providing proton therapy. They will meet with you once a week to review your progress and discuss any questions or concerns you may have. All of our physicians are specialists in proton therapy and treat all disease types.

The radiation oncologists who provide clinical care at Fred Hutch are all members of the UW Physicians Group and hold faculty positions within the UW School of Medicine. Having trained at some of the best cancer centers in the country, including UW Medicine, Harvard, Cornell, MD Anderson, Stanford, Georgetown, Johns Hopkins and Memorial Sloan-Kettering Cancer Center, they are leaders in their field and known for clinical excellence. With specializations in brain, head and neck, breast, lung, gastrointestinal, genitourinary, prostate and childhood cancers, our physicians have the expertise to provide the highest level of medical care to our patients.

Our Radiation Oncologists

All of our physicians are specialists in proton therapy and treat all disease types.



Dr. Annemarie Shepherd Medical Director

Specialty: Thoracic cancer, mesothelioma and thymic tumors



Dr. Ralph Ermoian Specialty: Childhood cancers



Dr. Jim Apisarnthanarax Specialty: Gastrointestinal tumors



Dr. Jonathan Chen Specialty: Ocular and prostate cancers



Dr. Michael Folkert Specialty: Genitourinary cancers and sarcoma



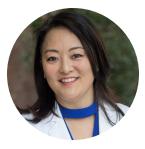
Dr. Lia Halasz Specialty: Brain/Central Nervous System (CNS) cancers



Dr. Ed Kim Specialty: Gastrointestinal and soft tissue cancers



Dr. John Kang Specialty: Lung and thoracic cancers



Dr. Janice Kim Specialty: Breast cancer



Dr. Sara Hardy Specialty: Central Nervous System (CNS) cancers



Dr. Kylie Kang Specialty: Breast cancer



Dr. Jay Liao Specialty: Head and neck tumors and genitourinary cancers



Dr. Simon Lo Specialty: CNS cancers



Dr. Neil Panjwani Specialty: Head and neck tumors



Dr. Martin Ma Specialty: Prostate cancer



Dr. Ramesh Rengan Former Medical Director Specialty: Lung, ocular and prostate cancers and melanoma



Dr. Lisa Ni Specialty: Pediatric and Central Nervous System (CNS) cancers



Dr. Stephanie Schaub Specialty: Sarcoma of adult and pediatric patients



Dr. Jamie Takayesu Specialty: Gastrointestinal and skin cancers



Dr. Jing Zeng Former Medical Director Specialty: Thoracic and genitourinary cancers



Dr. Yolanda Tseng Specialty: CNS cancers and lymphoma



Dr. Winston Vuong Specialty: Genitourinary cancers

Our Advanced Practice Providers



David Astaphan, PA-C



Layne Chapple, ARNP



Jen Flannery, PA-C

Our Patient Care Coordinators



Cassidy Department Manager



Christine Appeals Coordinator



Jaemy



Matt Supervisor



Candice Lead



Erik



Adam

Jennette



Jennifer

Our Patient Care Coordinators, continued



Morgan



Vandela

Our Schedulers



Dana Supervisor



Jenny



Tina

Our Health Information Management Specialists



Phuong Lead



Ryan

Our Patient Navigators



April Department Manager



lan Lead



Annie



Gill



Katie



Chris Program Department Coordinator

Our Patient and Family Support Staff



Elizabeth Social Worker



Laura Nutritionist



Erin Child Life Specialist



Kyle Spiritual Health Clinician



Laurel Child Life Specialist

Our Nurses



Amanda N. Department Manager



Megann Supervisor



Amanda L.



Angelle



Betty



Darlene



Gloria



Jessica



Jordan



Micah



Steve

Our Medical Assistants



Jade



Sita

Our Radiation Therapists



John Department Manager



Jillian



Katelyn



Aja

Kat

Nely



lvana



Kate



Nicole



Connecting with other patients

Our Radiation Therapists, continued



Patrick



Paul



Ruben



Terry



Tiffany



Trang

Your core care team

- Care team nurses provide care and help coordinate additional medical services you might need during your proton treatment. Your care team nurse is a registered nurse with experience in radiation therapy.
- Radiation therapists make sure you are positioned comfortably and correctly. They will deliver your daily treatment and remain close while you receive therapy.
- Radiation oncologists direct your care and meet with you once a week to review your progress and discuss any questions or concerns you may have.
- Child Life specialists are skilled and caring pediatric health care professionals who explain proton therapy using language and visual aids pediatric patients understand. They also teach methods to help young patients relax, express their feelings, and understand medical procedures.
- Patient care coordinators coordinate the exchange of records, collect information for evaluating your individual care, and schedule your consult, CT simulation and follow up appointments. They also help you with insurance, Medicare or Medicaid coverage, and coordinating payments.
- Patient navigator/concierges provide concierge-type service from the time before you arrive at Fred Hutch to the end of your treatment.
- Schedulers arrange your treatment appointments and weekly visits with your radiation oncologist and nurse. (OTVs)

Your extended team

- Medical physicists monitor the equipment and procedures used in therapy to make sure radiation is delivered safely and effectively. They run checks on your treatment plan to make sure the correct dose of protons targets your tumor.
- Medical dosimetrists work with your doctor to prepare your treatment plan. They calculate the angles and doses of proton energy required to treat your tumor, while ensuring your healthy tissue is exposed to as little radiation as possible.
- Machinists create custom treatment devices that are used for certain patients.
- Engineers monitor and ensure the system and equipment output is accurate and precise.
- Administrative staff manage office and business functions and help with your insurance claims.
- Facilities staff maintain the building and ensure it is clean and safe for our patients.

Important phone numbers

Emergency? Call 911

Proton Therapy Main number

If you have questions or are running late for your proton therapy appointment, please call us at **(206) 306-2800**.

Clinical issues/questions (including questions about side effects):

During business hours (7 a.m.–5 p.m.):

- Call your nurse first at their direct number, or call (206) 306-2803.
- If they do not answer, please leave a voicemail or send a message via MyChart, and they will return your call as soon as they are able.

After hours and weekends:

- Call **(206) 598-6190.**
- Urgently need to speak to a doctor? Call **(206) 598-6190** and ask to have the on-call radiation oncologist paged.
- If you're able to wait, leave a message for your nurse and your call will be returned the next business day.

Prescription refills:

If your radiation oncologist prescribed medication and you need a refill, please request it through MyChart, or call **(206) 306-2803**. Please provide one-week notice.

Scheduling issues/questions:

Day of your appointment:

Call your treatment room as soon as possible if you are unable to keep an appointment or will be late. If they do not answer, please leave a voicemail

Direct numbers for Treatment Rooms

Room 1: (206) 306-2852 Room 2: (206) 306-2850 Room 3: (206) 306-2848 Room 4/Gantry: (206) 306-2846

Important phone numbers, continued

Transportation or lodging information:

Please contact our patient navigator/concierge team at (206) 306-2028 or Concierge.Proton@fredhutch.org.

Financial/insurance questions:

Contact your patient care coordinator at (206) 306-2800.

Billing information:

Fred Hutch bills your care in two parts: a physician fee from UW Physicians (UWP) and a facility fee from Fred Hutch.

• The facility fee is for the equipment and supplies used to deliver your treatment. This may include charges for equipment used in the delivery of proton therapy, supplies and scans. Clinic and facility charges may be greater than the charges for professional services, depending on the service provided.

For all questions regarding your facility fee bill, or to make payments, call Fred Hutch Billing at **(206) 606-6226** or email **fincounsel@fredhutch.org.**

• The UW Physician fee (UWP) includes charges for professional clinical services provided during your treatment, including outpatient clinic services provided by or under the supervision of a physician. Clinic and facility charges may be greater than the charges for professional clinical services, depending on the service provided.

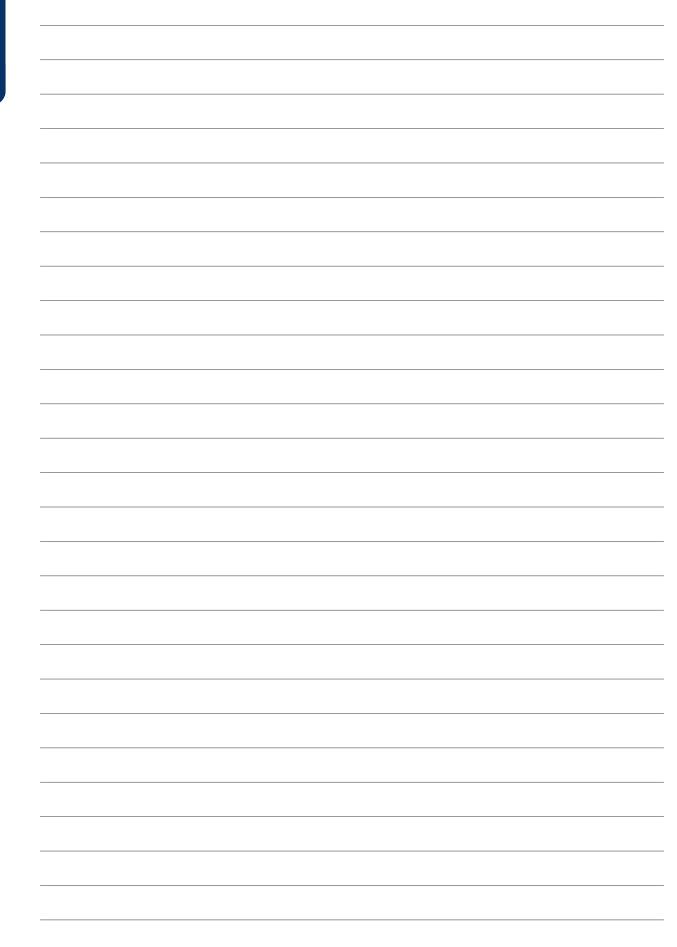
For questions about your UWP bill or to make payments, call UWP at **(206) 543-8606** (option 0) or the toll-free number at **(888) 234-5467** (option 0).

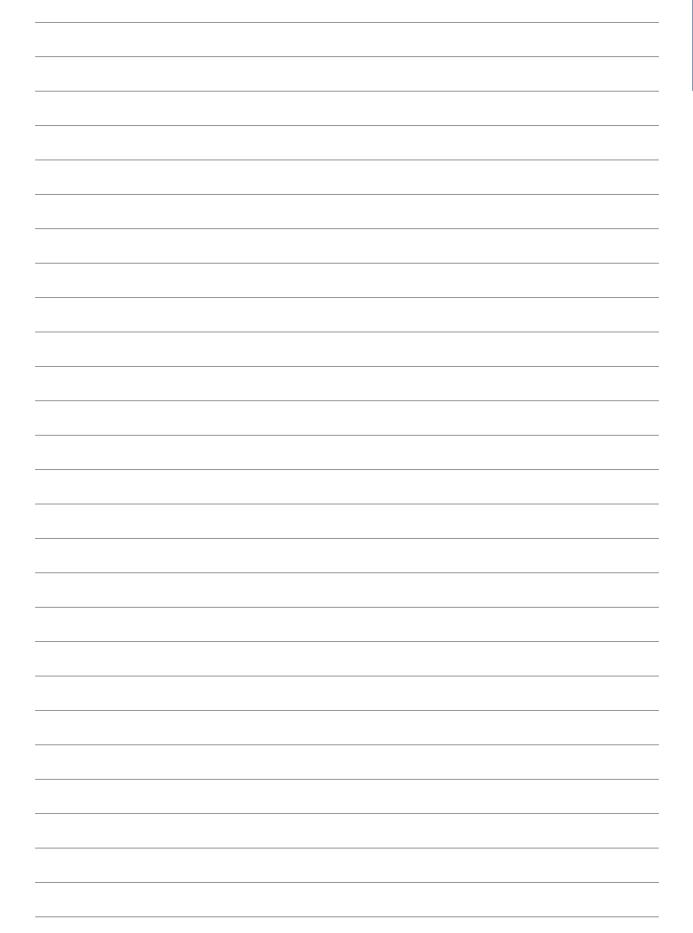
Interpreter services

Please let us know if you will need an interpreter for your appointments at Fred Hutch. We can arrange for specially-trained medical interpreters for patients or family members who do not speak English.

If you have questions, phone (206) 606-6419.

Notes	5	





Fred Hutch Cancer Center - Proton Therapy

1570 N. 115th Street, Seattle, WA 98133 | (206) 306-2028 FredHutch.org/ProtonTherapy

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