

About Your Intrathecal Radioimmunotherapy (RIT) for Pediatric Patients

This guide will help you get ready for your intrathecal radioimmunotherapy (RIT) at Memorial Sloan Kettering (MSK). It will also help you understand what to expect during and after your treatment.

Read through this guide at least once before your treatment and use it as a reference in the days leading up to your treatment. Bring this guide with you every time you come to MSK, including the day of your treatment. You and your healthcare team will refer to it throughout your care.

In this resource, the words “you” and “your” refer to you or your child.

Your Healthcare Team

Oncologist (cancer doctor): _____

Nurse Practitioner (NP): _____

Phone number: _____



To view this guide online, visit www.mskcc.org/pe/intrathecal_RIT_peds

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About Your Treatment

About Radioimmunotherapy (RIT)

RIT is a type of treatment that combines radiation therapy and immunotherapy. With RIT, radiolabeled monoclonal antibodies deliver radiation directly to the cancer cells.

- An **antibody** is a protein that's made by your immune system and released into your blood.
- A **radiolabeled monoclonal antibody** is an antibody that's made in a lab and specially designed to attach to cancer cells. The antibody has liquid radiation attached to it (see Figure 1). This radiation kills the cancer cells directly without damaging normal tissue.

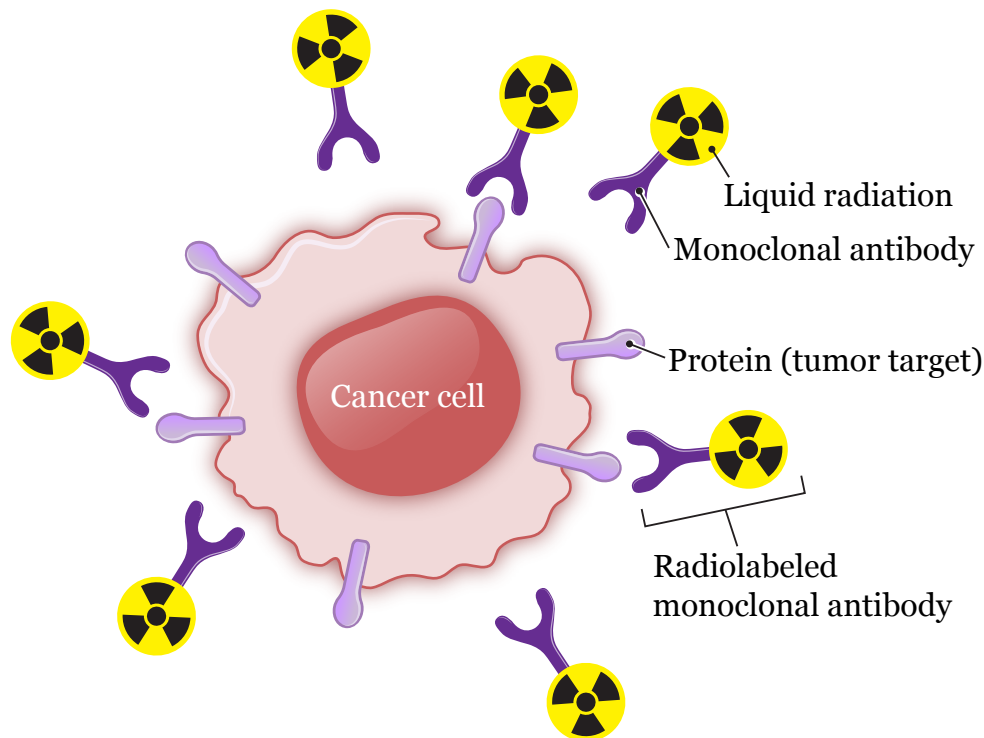


Figure 1. Radiolabeled monoclonal antibody

About Intrathecal RIT

MSK is doing a clinical trial (research study) using a treatment called intrathecal RIT. Intrathecal RIT can be used to treat certain types of cancer in your brain, spine, and leptomeninges (thin layers of tissue around your brain and spinal cord).

With intrathecal RIT, radiolabeled monoclonal antibodies are put into your cerebrospinal fluid (CSF). CSF is the liquid around your brain and spinal cord. It's made in the ventricles (hollow spaces) in your brain.

The radiolabeled monoclonal antibodies are usually injected into your CSF using an Ommaya reservoir. An Ommaya reservoir is a quarter-sized, soft, plastic, dome-shaped device that's placed under your scalp during a surgery. It's connected to a catheter (thin, flexible tube) that's placed in one of the ventricles in your brain. For more information, read the resource *Frequently Asked Questions About Ommaya Reservoirs and Ommaya Taps for Pediatric Patients* (www.mskcc.org/pe/faq_ommay_a_reservoirs_taps).

If you already have a programmable ventriculoperitoneal (VP) shunt, the radiolabeled monoclonal antibodies can be injected into your CSF using the VP shunt reservoir. If you have a nonprogrammable VP shunt, your neurosurgeon may be able to change it to a programmable VP shunt.

Your Intrathecal RIT Treatment Schedule

The radiolabeled monoclonal antibody injections are given in 2 cycles (sometimes called rounds). Each cycle lasts for 4 weeks.

- During week 1, you'll get the antibody injection.
- During weeks 2, 3, and 4, you'll have physical and neurologic exams at least once a week. You may have other tests (such as imaging scans, blood tests, or Ommaya or VP shunt taps) if needed.

Your healthcare provider will talk with you about what to expect.

Your Treatment Team

You'll have many different healthcare providers working together before, during, and after your treatment. Your treatment team will include your:

- Neurosurgeon
- Oncologist (cancer doctor)
- Neurologist
- Neuropsychologist
- Nurse practitioner (NP)
- Nuclear medicine doctor
- Radiation safety officer
- Pediatric nurse
- Child life specialist
- Social worker

A financial counselor is also available to talk with you about any insurance issues you may have. Please bring all your insurance information to your appointment. If you have questions about insurance, call Patient Financial Services at 212-639-3810.

The information in this section will help you get ready for your treatment. Read through this section when your treatment is scheduled and refer to it as your start date gets closer. It has important information about what you need to do before your treatment.

Write down your questions and be sure to ask your healthcare provider.

Notes _____

Getting Ready for Your Treatment

Meet With Your Healthcare Team

Before you start treatment, you'll meet with your oncologist and NP. They'll talk with you about the details of your treatment, including side effects you may have and what to expect before, during, and after your treatment. They'll ask you to sign a consent form. They may also recommend that you see other healthcare providers, such as a child life specialist or social worker.

Have Tumor Testing, If Needed

Depending on the type of tumor you have, you may need testing to see if the radiolabeled monoclonal antibodies will attach to the tumor. If the antibodies don't attach to the tumor, you can't have intrathecal RIT. Your oncologist will talk with you about this.

Have an Ommaya Reservoir Placed, If Needed

If you don't already have an Ommaya reservoir or VP shunt, you need to have an Ommaya reservoir placed before you start intrathecal RIT.

Your Ommaya reservoir will be placed during a surgery. Your oncologist or NP will arrange for you to meet with your neurosurgeon and talk with you about what to expect. For more information, read the resource *About Your Ommaya Reservoir Placement Surgery for Pediatric Patients* (www.mskcc.org/pe/ommaya_reservoir_surgery).

Have Your Nonprogrammable VP Shunt Changed to a Programmable VP Shunt, If Needed

If you have a nonprogrammable VP shunt, your neurosurgeon may be able to change it to a programmable VP shunt that can be used for your intrathecal RIT. To do this, they'll change the shunt valve during a surgery. Your oncologist or NP will arrange for you to meet with your neurosurgeon and talk with you about what to expect.

For more information, read the resources *About Your Ventriculoperitoneal (VP) Shunt Surgery for Pediatric Patients* (www.mskcc.org/pe/vp_shunt_surgery_peds) and *About Your Programmable VP Shunt for Pediatric Patients* (www.mskcc.org/pe/programmable_vp_shunt_peds).

Arrange for Housing, If Needed

The Ronald McDonald House provides temporary housing for out-of-town pediatric cancer patients and their families. MSK also has arrangements with several local hotels and housing facilities that may give you a special lower rate. Your social worker can talk with you about your options and help you make reservations.

After each antibody injection, you'll give off radiation. The radiation will fade over time, but it'll be strongest right after the antibody injection. Because of this, you can't stay at the Ronald McDonald house the night after each antibody injection. You must stay at a hotel instead. Make sure to book this before the day of your treatment. Your social worker can help you.

Choose a Caregiver

It's important that your caregiver isn't pregnant. The radiation you'll give off after each antibody injection can harm the fetus (unborn baby).

Within 4 Weeks of Your First Antibody Injection

You'll need to have the following exams and tests to make sure intrathecal RIT is safe for you:

- A physical exam
- A neurological exam
- Blood tests to check your blood counts, blood type, blood clotting, and kidney, liver, and thyroid function
- A pregnancy test (if you're able to have children)
- Tests to check for cancer cells in your CSF
- Magnetic resonance imaging (MRI) scans
- A CSF flow study
- A neuropsychological evaluation

MRI Scans

MRI scans help your care team make sure you don't have any new or growing cancer. You'll have MRI scans of your brain and spine.



Use this area to write your MRI information.

Date (MRI Brain): _____ Time: _____

Date (MRI Spine): _____ Time: _____

CSF Flow Study

A CSF flow study is done to make sure your Ommaya reservoir or programmable VP shunt reservoir is working well.

During the flow study, your NP or doctor will inject a radioactive dye into your reservoir. Then, you'll have nuclear medicine scans to see how well the dye moves through your CSF. You may have scans:

- Right after the dye is injected
- About 1 to 4 hours after the dye is injected
- About 18 to 24 hours after the dye is injected
- About 48 hours after the dye is injected (if needed)



Use this area to write your CSF flow study information.

Dye injection: Date: _____ Time: _____

First follow-up scan: Date: _____ Time: _____

Second follow-up scan: Date: _____ Time: _____

Third follow-up scan: Date: _____ Time: _____

Instructions Before Scans with Sedation

If you're getting a sedative (medication to make you sleepy) during your MRI or CSF flow study scans, you need to stop eating and drinking for a certain amount of time before your scan. Your NP will talk with you about when you need to stop eating and drinking. If you don't follow the instructions they give you, your scans may be canceled.



Use this area to write your instructions for eating and drinking before your scans with sedation.

Neuropsychological Evaluation

Having a neuropsychological evaluation before you start treatment will help your care team notice any changes in your cognition (thinking), emotions (feelings), or behavior (actions) during or after your treatment.

During your appointment, you'll meet with a specially trained pediatric neuropsychologist. The neuropsychologist will check your attention, memory, and other parts of your cognition. Depending on how old you are, they may also assess your social, emotional, and behavioral strengths and overall well-being.



Use this area to write your neuropsychological evaluation information.

Date: _____ Time: _____

The information in this section will tell you what to expect during your treatment, including the procedures you'll have and the medications you'll take.

Write down your questions and be sure to ask your healthcare provider.

Notes _____

7 Days Before Your Antibody Injection

Start Taking Potassium Iodide (SSKI®) and Liothyronine (Cytomel®)

You'll need to take potassium iodide and liothyronine before and after each injection. Potassium iodide and liothyronine are medications to help protect your thyroid during your treatment. Your healthcare provider will give you a prescription.

Start taking potassium iodide and liothyronine 7 days before each antibody injection. Keep taking them every day until 2 weeks after each antibody injection. Your oncologist or NP will tell you what dose (amount) to take and when to start and stop taking them. To help you remember, you can write down the information in the resource *Medication Instructions Before Your Intrathecal Radioimmunotherapy (RIT) Injections*, located in the “Educational Resources” section.

Your oncologist or NP will give you a medication diary. Use it to record the potassium iodide and liothyronine you take. Write your initials in each box when you take your medication. Be sure to write any missed doses in your diary. Bring your diary to all your appointments.



Take the potassium iodide (SSKI) and liothyronine (Cytomel) until the end date your oncologist or NP gave you. Read your medication diary for more information.

The Night Before Your Antibody Injection

Start Taking Dexamethasone (Decadron®) and an Antacid

Dexamethasone is a steroid medication that helps control inflammation (swelling).

Start taking dexamethasone the night before each antibody injection. You'll take a total of 6 doses of dexamethasone for each injection:

- 1 dose the night before each injection.
- 2 doses in clinic on the day of each injection. A nurse will give you these doses.
- 2 doses the day after each injection.
- 1 dose the second day after each injection.

Sometimes, dexamethasone can upset your stomach. Taking an antacid on the days you take the dexamethasone can help prevent this. For most people, your healthcare provider will give you a prescription for a liquid antacid. On the day of your antibody injections, a nurse will give you the antacid in clinic.

Your oncologist or NP will tell you what doses to take and exactly when to start and stop taking these medications. To help you remember, you can write down the information in the resource *Medication Instructions Before Your Intrathecal Radioimmunotherapy (RIT) Injections*, located in the “Educational Resources” section.

The Day of Your Antibody Injection

Your appointment time will be between 8:00 AM and 9:00 AM. **Please arrive on time.**

Where to Go

Your appointments will be at the Pediatric Ambulatory Care Center (PACC). The PACC is located at Memorial Hospital (MSK's main hospital). The address is:

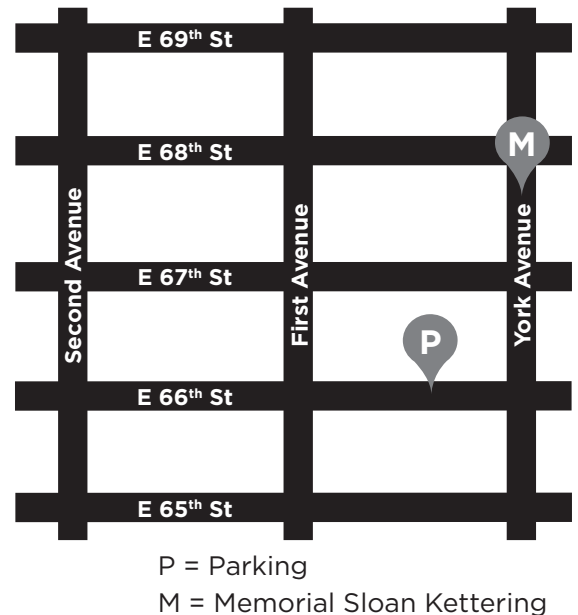
Memorial Hospital
1275 York Avenue (between East 67th and East 68th Streets)
New York, NY 10065
Take the B elevator to the 9th floor

Where to Park

MSK's parking garage is located on East 66th Street between York and First Avenues. If you have questions about prices, call 212-639-2338.

To reach the garage, turn onto East 66th Street from York Avenue. The garage is located about a quarter of a block in from York Avenue, on the right-hand (north) side of the street. There's a tunnel that you can walk through that connects the garage to the hospital.

There are also other garages located on East 69th Street between First and Second Avenues, East 67th Street between York and First Avenues, and East 65th Street between First and Second Avenues.



Before Your Antibody Injection

Your antibody injections will be given in a private room in the PACC. If you had side effects after your last antibody injection or have a high risk of side effects, you may be admitted to the hospital before your injection. This is very rare.

You'll have a physical exam and blood tests done before each injection. You'll need to wait for a few hours between the blood tests and your antibody injection. During this time, you must stay in the PACC area. You can go on the computer or play in the playroom.

You'll also get a medication to prevent nausea (feeling like you're going to throw up), acetaminophen (Tylenol®) to prevent fever, and an antihistamine to prevent an allergic reaction. You may also get pain medication or medication to help with anxiety.

During Your Antibody Injection

Your NP or doctor will give your antibody injection while you're in the bed in your PACC room. You don't need to do anything to get ready for it.

- If you have an Ommaya reservoir, your NP or doctor will inject the antibodies into your Ommaya reservoir during a procedure called an Ommaya reservoir tap (see Figure 2). For more information, read the resource *Frequently Asked Questions About Ommaya Reservoirs and Ommaya Taps for Pediatric Patients* (www.mskcc.org/pe/faq_ommaya_reservoirs_taps).
- If you have a programmable VP shunt, your NP or doctor will turn off your shunt and inject the antibodies into the shunt's reservoir. Your shunt will stay off for about 4 hours. Tell your healthcare provider if you have a headache, pain, nausea, or vomiting (throwing up) while it's off. After about 4 hours, your NP or doctor will turn your shunt back on and change it back to the original setting.

You may be asked to lie on your back during your procedure. When you're ready, your NP or doctor will clean the skin over the top of your Ommaya reservoir or programmable VP shunt with providone-iodine (Betadine®). Tell them if you're allergic to iodine. They'll use a different solution.

Once your skin is clean, your NP or doctor will put a small butterfly needle with tubing attached into your reservoir. They'll take out a small amount of your CSF using a syringe that's attached to the tubing (see Figure 2). This is done to make room for the antibodies. This CSF might be sent to the Pathology Department for testing. Then, your NP or doctor will slowly inject the antibody into your Ommaya reservoir or programmable VP shunt reservoir. This usually doesn't hurt.

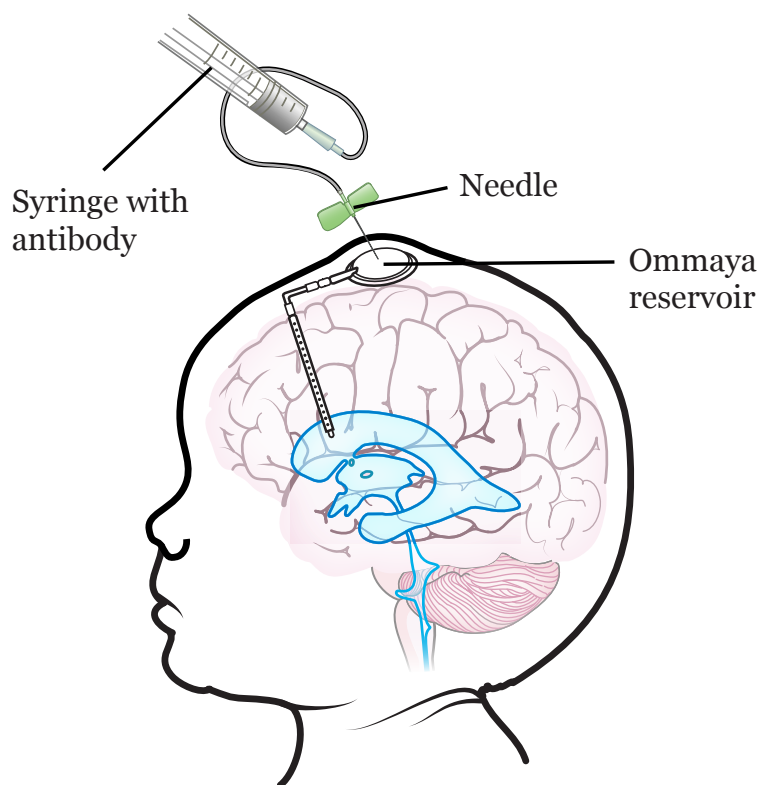


Figure 2. Antibody injection into an Ommaya reservoir

After the injection, your NP or doctor will remove the butterfly needle from your Ommaya reservoir or programmable VP shunt reservoir. They'll place a dry sterile bandage or Band Aid® over the injection site.

You'll stay at the PACC for about 4 hours after each injection. During that time, your healthcare providers will watch you for side effects (such as a fever, headache, nausea, or an allergic reaction). Most people don't have side effects and are discharged from the PACC about 4 hours after their injection.

If you do have side effects, they can usually be managed in the PACC. Some people will need to be admitted to the hospital to manage side effects. This is rare.

After Your Antibody Injection

You can wash your hair as usual after the tap.

Radiation Safety Precautions

You'll be radioactive (give off radiation) for a period of time after each antibody injection. Some of the radiation will leave your body through urine (pee) and other body fluids. You'll need to be careful so people near you aren't exposed to too much radiation.

Your radiation safety officer will go over the safety precautions you will need to follow after each antibody injection. They'll tell you what you need to do and for how long. They'll also give you written instructions to follow. If you have any questions about radiation safety, call 212-639-7391 Monday through Friday from 9:00 AM to 5:00 PM.

Follow these general radiation safety precautions to avoid exposing other people to radiation.

- **Tell us if anyone who's caring for you is pregnant or if you're staying at the Ronald McDonald House.**
- Avoid public areas.
- Don't use public transportation (such as a bus or train) to get home after your antibody injection. If you're driving or taking a taxi home, sit as far away from the driver and other passengers you as you can.
- Avoid long periods of close physical contact with other people. It's OK to be close to another person for a short period of time (such as a brief hug), but you should stay at least 6 feet away from other people most of the time.
- Don't share a bed with anyone.

Some of the radiation will leave your body in your body fluids (such as blood, urine, and vomit). Follow the guidelines below to help manage this.

- Flush the toilet twice after using it.
- Practice good hygiene, such as washing your hands well with soap and water after using the bathroom.

- If you're caring for the patient, wear gloves when touching blood, urine, vomit, and other body fluids. Wash your hands well after you take the gloves off.
- Separate items with lots of body fluids (such as diapers) from normal trash for 2 weeks after each antibody injection. Store these items in an area away from people for 3 months. After 3 months, you can throw them away with your normal household trash.
 - **If this isn't possible, call your local sanitation department to find out other ways to get rid of radioactive waste.**
 - **If you're staying at the Ronald McDonald House, talk with a Ronald McDonald House employee about the right way to throw away diapers and vomit.**
- Wash your clothes, bed linens, bathroom linens, and plush toys in warm water separate from other laundry.

Use this space to write down your questions for the radiation safety officer.

Radiation Safety Wallet Card

Some types of security equipment (such as at the airport or outside a tunnel) can detect very small amounts of radiation. A staff member will give you a card that says you got radioactive medication and may give off small amounts of radioactivity for up to 3 months after your treatment. **Carry this card with you at all times.** If you need emergency medical care or are stopped by law enforcement, show them this card.

Medications

For 24 Hours After Each Antibody Injection

Take acetaminophen (Tylenol®) every 4 to 6 hours for 24 hours after your antibody injection. This will help prevent fever and pain. You can also take anti-nausea and pain medications as directed. Your oncologist or NP will go over these medications with you.

The Day After Each Antibody Injection

- Keep taking dexamethasone twice a day with an antacid.
- Keep taking potassium iodide and liothyronine until the end date your oncologist gave you.

2 Days After Each Antibody Injection

- Take the last dose of dexamethasone with an antacid.
- Keep taking potassium iodide and liothyronine until the end date your oncologist gave you.

Around 2 Weeks After Each Antibody Injection

Around 2 weeks after each antibody injection, you can stop taking the potassium iodide and liothyronine. Your oncologist or NP will tell you what date you should stop.

Remember to write each dose you take in your medication diary. Be sure to write any missed doses in your diary. Bring your diary to all your appointments.

Complete your medication diary, sign it, and give it to your oncologist or NP.



Use this area to write your last day to take the potassium iodide (SSKI) and liothyronine (Cytomel).

Date: _____

Follow-Up Appointments

You'll have follow-up appointments with your oncologist or NP at least once a week for 3 weeks after each antibody injection. Your follow-up appointments and scans must be done at MSK unless your healthcare provider tells you otherwise. Bring your medication diary to all your appointments.

During these appointments, you'll have detailed physical and neurological exams. You may also have imaging scans, blood tests, and an Ommaya or shunt tap during some appointments.

3 Weeks After Each Antibody Injection

About 3 weeks after each antibody injection, you'll have:

- MRI scans of your brain and spine
- An Ommaya reservoir or programmable VP shunt reservoir tap
- Blood samples taken
- A physical and neurological exam

Scans with Sedation

If you're getting a sedative during your scans, you need to stop eating and drinking for a certain amount of time before your scan. Your NP will talk with you about when you need to stop eating and drinking. **If you don't follow the instructions they give you, your scans may be canceled.**



Use this area to write your instructions for eating and drinking before your scans with sedation.

Use the chart below to write your appointment information. Write your appointment date, time, and which healthcare provider you're seeing. Use checkmarks to show which tests will be done.

When do I come?

Who will I see?

What tests will be done?

When do I come?		Who will I see?	What tests will be done?						
Date	Time	Healthcare Provider	Neurological Exam	Neuropsychological Exam	Blood Tests	Ommaya or VP Shunt Tap	MRI Scan	Other	

6 Months After Your First Antibody Injection

About 6 months after your first antibody injection, you'll have:

- MRI scans of your brain and spine
- An Ommaya reservoir or programmable VP shunt reservoir tap
- Blood samples taken
- A physical and neurological exam



Use this area to write your appointment and scan information.

Date (Clinic Appointment): _____ Time: _____

Date (MRI Brain): _____ Time: _____

Date (MRI Spine): _____ Time: _____

Scans with Sedation

If you're getting a sedative during your scans, you need to stop eating and drinking for a certain amount of time before your scan. Your NP will talk with you about when you need to stop eating and drinking. If you don't follow the instructions they give you, your scans may be canceled.



Use this area to write your instructions for eating and drinking before your scans with a sedation.

Follow-up Neuropsychological Care

You'll have neurocognitive function, neurodevelopmental, and quality of life testing done before each antibody injection cycle, about every 4 to 5 weeks while you're getting intrathecal RIT, and about 3 to 6 months after your last antibody injection. After that, you'll have appointment for neuropsychological care once every year.



Use this area to write your appointment information.

Date: _____ Time: _____

When to Contact Your Healthcare Provider



Call your healthcare provider right away if you have:

- A fever of 100.4 °F (38.0 °C) or higher
- Increased pain
- Increased sleepiness
- Severe headaches
- Severe nausea and vomiting
- Any other questions or concerns

If you have any questions or concerns, talk with your oncologist or NP. You can reach them Monday through Friday from 9:00 AM to 5:00 PM. Call the office directly at 212-639-3751 (neuro-oncology patients) or 212-639-6410 (neuroblastoma patients).

After 5:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask for the pediatric oncology fellow on call.

To speak with a social worker, call the Social Work department at 212-639-7020.

This section includes a list of support services that may help you get ready for your treatment and recover safely.

Write down your questions and be sure to ask your healthcare provider.

Notes _____

MSK Support Services

Admitting Office

212-639-7606

Call if you have questions about your hospital admission, including requesting a private room.

Anesthesia

212-639-6840

Call if you have questions about anesthesia or sedation.

Blood Donor Room

212-639-7643

Call for more information if you're interested in donating blood or platelets.

Bobst International Center

888-675-7722

MSK welcomes patients from around the world. If you're an international patient, call for help arranging your care.

Chaplaincy Service

212-639-5982

At MSK, our chaplains are available to listen, help support family members, pray, contact community clergy or faith groups, or simply be a comforting companion and a spiritual presence. Anyone can request spiritual support, regardless of formal religious affiliation. The interfaith chapel is located near Memorial Hospital's main lobby and is open 24 hours a day. If you have an emergency, please call the hospital operator and ask for the chaplain on call.

Counseling Center

646-888-0200

Many people find that counseling helps them. We provide counseling for individuals, couples, families, and groups, as well as medications to help if you feel anxious or depressed. To make an appointment, ask your healthcare provider for a referral or call the number above.

Food Pantry Program

646-888-8055

The food pantry program provides food to people in need during their cancer treatment. For more information, talk with your healthcare provider or call the number above.

Integrative Medicine Service

646-888-0800

Integrative Medicine Service offers patients many services to complement traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy.

Look Good Feel Better Program

www.lookgoodfeelbetter.org

800-395-LOOK (800-395-5665)

This program offers workshops to learn things you can do to help you feel better about your appearance. For more information or to sign up for a workshop, call the number above or visit the program's website.

MSK Library

library.mskcc.org

212-639-7439

You can visit our library website or speak with the library reference staff to find more information about your specific cancer type. You can also visit LibGuides on MSK's library website at libguides.mskcc.org.

Patient and Caregiver Education

www.mskcc.org/pe

Visit the Patient and Caregiver Education website to search our virtual library. There, you can find written educational resources, videos, and online programs.

Patient and Caregiver Peer Support Program

212-639-5007

You may find it comforting to speak with someone who has been through a treatment similar to yours. You can talk with a former MSK patient or caregiver through our Patient and Caregiver Peer Support Program. These conversations are confidential. They may take place in person or over the phone.

Patient Billing

646-227-3378

Call if you have questions about preauthorization with your insurance company. This is also called preapproval.

Patient Representative Office

212-639-7202

Call if you have questions about the Health Care Proxy form or if you have concerns about your care.

Perioperative Nurse Liaison

212-639-5935

Call if you have questions about MSK releasing any information while you're having surgery.

Private Duty Nursing Office

212-639-6892

You may request private nurses or companions. Call for more information.

Resources for Life After Cancer (RLAC) Program

646-888-8106

At MSK, care doesn't end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Sexual Health Programs

Cancer and cancer treatments can have an impact on your sexual health. MSK's Sexual Health Programs can help you take action and address sexual health issues before, during, or after your treatment.

- Our Female Sexual Medicine and Women's Health Program helps women who are dealing with cancer-related sexual health challenges, including premature menopause and fertility issues. For more information, or to make an appointment, call 646-888-5076.
- Our Male Sexual and Reproductive Medicine Program helps men who are dealing with cancer-related sexual health challenges, including erectile dysfunction. For more information, or to make an appointment, call 646-888-6024.

Social Work

212-639-7020

Social workers help patients, family, and friends deal with issues that are common for people with cancer. They provide individual counseling and support groups throughout the course of treatment and can help you communicate with children and other family members. Our social workers can also help refer you to community agencies and programs, as well as financial resources if you're eligible.

Tobacco Treatment Program

212-610-0507

If you want to quit smoking, MSK has specialists who can help. Call for more information.

Virtual Programs

www.mskcc.org/vp

MSK's Virtual Programs offer online education and support for patients and caregivers, even when you can't come to MSK in person. Through live, interactive sessions, you can learn about your diagnosis, what to expect during treatment, and how to prepare for the various stages of your cancer care. Sessions are confidential, free, and led by expert clinical staff. If you're interested in joining a Virtual Program, visit our website at www.mskcc.org/vp for more information.

For more online information, visit the "Cancer Types" section of www.mskcc.org.

External Support Services

Access-A-Ride

web.mta.info/nyct/paratran/guide.htm

877-337-2017

In New York City, the MTA offers a shared ride, door-to-door service for people with disabilities who aren't able to take the public bus or subway.

Air Charity Network

www.aircharitynetwork.org

877-621-7177

Provides travel to treatment centers.

American Cancer Society (ACS)

www.cancer.org

800-ACS-2345 (800-227-2345)

Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

Cancer and Careers

www.cancerandcareers.org

A resource for education, tools, and events for employees with cancer.

CancerCare

www.cancer.org

800-813-4673

275 Seventh Avenue (Between West 25th & 26th Streets)

New York, NY 10001

Provides counseling, support groups, educational workshops, publications, and financial assistance.

Cancer Support Community

www.cancersupportcommunity.org

Provides support and education to people affected by cancer.

Caregiver Action Network

www.caregiveraction.org

800-896-3650

Provides education and support for those who care for loved ones with a chronic illness or disability.

Corporate Angel Network

www.corpangelnetwork.org

866-328-1313

Offers free travel to treatment across the country using empty seats on corporate jets.

Gilda's Club

www.gildasclubnyc.org

212-647-9700

A place where men, women, and children living with cancer find social and emotional support through networking, workshops, lectures, and social activities.

Good Days

www.mygooddays.org

877-968-7233

Offers financial assistance to pay for copayments during treatment. Patients must have medical insurance, meet the income criteria, and be prescribed medication that is part of the Good Days formulary.

Healthwell Foundation

www.healthwellfoundation.org

800-675-8416

Provides financial assistance to cover copayments, health care premiums, and deductibles for certain medications and therapies.

Joe's House

www.joeshouse.org

877-563-7468

Provides a list of places to stay near treatment centers for people with cancer and their families.

LGBT Cancer Project

www.lgbtcancer.org

Provides support and advocacy for the LGBT community, including online support groups and a database of LGBT-friendly clinical trials.

LIVESTRONG Fertility

www.livestrong.org/we-can-help/fertility-services

855-744-7777

Provides reproductive information and support to cancer patients and survivors whose medical treatments have risks associated with infertility.

National Cancer Institute

www.cancer.gov

800-4-CANCER (800-422-6237)

National Cancer Legal Services Network

www.nclsn.org

Free cancer legal advocacy program.

National LGBT Cancer Network

www.cancer-network.org

Provides education, training, and advocacy for LGBT cancer survivors and those at risk.

Needy Meds

www.needymeds.org

Lists Patient Assistance Programs for brand and generic name medications.

NYRx

www.nyrxplan.com

Provides prescription benefits to eligible employees and retirees of public sector employers in New York State.

Partnership for Prescription Assistance

www.pparx.org

888-477-2669

Helps qualifying patients without prescription drug coverage get free or low-cost medications.

Patient Access Network Foundation

www.panfoundation.org

866-316-7263

Provides assistance with copayments for patients with insurance.

Patient Advocate Foundation

www.patientadvocate.org

800-532-5274

Provides access to care, financial assistance, insurance assistance, job retention assistance, and access to the national underinsured resource directory.

RxHope

www.rxhope.com

877-267-0517

Provides assistance to help people get medications that they have trouble affording.

This section contains the educational resources that were referred to throughout this guide. These resources will help you get ready for your surgery and recover safely after surgery.

Write down your questions and be sure to ask your doctor or nurse.

Notes _____

PATIENT & CAREGIVER EDUCATION

Medication Instructions Before Your Intrathecal RIT Injections

This information explains when to start taking certain medications before each of your intrathecal radioimmunotherapy (RIT) antibody injections. Your nurse practitioner (NP) will fill in the information with you. Call them if you have questions.

Potassium Iodide (SSKI[®]) and Liothyronine (Cytomel[®])

Potassium iodide and liothyronine are medications to help protect your thyroid during your treatment. If you're getting an antibody injection radiolabeled with iodine, you'll need to take potassium iodide and liothyronine before and after each injection. Your healthcare provider will give you a prescription.

Start taking potassium iodide and liothyronine 7 days before each antibody injection. Keep taking them every day until 2 weeks after each antibody injection. Your oncologist or NP will tell you what dose (amount) to take and when to start and stop taking them. You can write the information in the table below to help you remember.

Start Date	End Date	Medication	Dose	How Often
		Potassium iodide (SSKI)		
		Liothyronine (Cytomel)		

Your oncologist or NP will give you a medication diary. Use it to record the potassium iodide and liothyronine you take. Write your initials in each box when you take your medication. Be sure to write any missed doses in your diary. Bring

your diary to all your appointments.



Take the potassium iodide (SSKI) and liothyronine (Cytomel) until the end date your oncologist or NP gave you.
Read your medication diary for more information.

Dexamethasone (Decadron®) and an Antacid

Dexamethasone is a steroid medication that helps control inflammation (swelling).

Start taking dexamethasone the night before each antibody injection.

You'll take a total of 6 doses of dexamethasone for each injection:

- 1 dose the night before each injection.
- 2 doses in clinic on the day of each injection. A nurse will give you these doses.
- 2 doses the day after each injection.
- 1 dose the second day after each injection.

Your oncologist or NP will tell you exactly what dose to take and when to start and stop taking it. You can write the information in the table below to help you remember.

Date	Morning	Evening
Night before injection: _____	<i>xxx</i>	Dexamethasone dose: _____
Day of injection: _____	<i>Dexamethasone given in clinic</i>	<i>Dexamethasone given in clinic</i>
Day after injection: _____	Dexamethasone dose: _____	Dexamethasone dose: _____
Two days after injection: _____	Dexamethasone dose: _____	<i>xxx</i>

Antacid Schedule

Sometimes, dexamethasone can upset your stomach. Taking an antacid on the days you take the dexamethasone can help prevent this. For most people, your healthcare provider will give you a prescription for a liquid antacid. On the day of your antibody injections, a nurse will give you the antacid in clinic.

Your oncologist or NP will tell you exactly what dose to take and when to start and stop taking it. You can write the information in the table below to help you remember.

Antacid Name	Dose	How Often

For more information about your intrathecal RIT, read the resource *About Your Intrathecal Radioimmunotherapy (RIT) for Pediatric Patients* (www.mskcc.org/pe/intrathecal_rit_peds).