About Your Intrathecal Radioimmunotherapy (RIT) for Pediatric Patients

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

Read through this guide and use it as a reference. 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.

For the rest of this resource, our use of the words “you” and “your” refers to you or your child.

Your Care Team

Doctor: ________________________________

Nurse Practitioner: ________________________________

Phone number: ________________________________

Fax number: ________________________________
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About Intrathecal RIT and Monoclonal Antibodies

MSK is doing a clinical trial (research study) using a treatment called intrathecal radioimmunotherapy (RIT). Intrathecal RIT uses antibodies to treat certain types of cancer in the brain, spine, and leptomeninges (membranes that surround the brain and the spinal cord). The antibody is delivered directly to the fluid surrounding your brain and spinal cord called cerebrospinal fluid (CSF). The type of antibody used in this treatment is called a monoclonal antibody. Below are common questions about intrathecal RIT.

What is an antibody?
An antibody is a protein that is made by your body’s immune system and released into your blood. Antibodies fight against harmful substances, such as bacteria, fungi, parasites, and viruses.

What is a radiolabeled monoclonal antibody?
A monoclonal antibody is an antibody that is made in a lab and is specially designed to attach to cancer cells. The antibody has liquid radiation attached to it. This radiation kills the cancer cells directly without damaging normal tissue in the brain or spine. This type of treatment is called radioimmunotherapy (RIT).

What happens during intrathecal RIT?
During intrathecal RIT, the monoclonal antibody is injected directly into your CSF through an Ommaya reservoir. An Ommaya reservoir is a quarter-sized, soft, plastic, dome-shaped device that is placed under your scalp during a surgery. If you already have a programmable ventriculoperitoneal (VP) shunt, the antibody can be injected into the VP shunt reservoir.
The information in this section will help you prepare for your treatment. Read through this section when your treatment is scheduled and refer to it as the date gets closer. It contains important information about what you need to do before your treatment.

Write down any questions you have and be sure to ask your doctor or nurse.
Preparing for Your Treatment

Meet With Your Doctor and Nurse Practitioner

You will meet with your doctor and nurse practitioner (NP) before you begin treatment. They will review the details of the treatment, including side effects and what to expect before, during, and after your treatment. You will be asked to sign a consent form. Your doctor or NP may also recommend that you see other healthcare providers, such as a child life specialist or social worker.

Your treatment team will include your doctor, NP, research nurse, nuclear medicine doctor, and radiation safety officer. Your radiation safety officer will go over the safety precautions that you will need to follow during your treatment.

A financial counselor will be available to meet with you to discuss any insurance issues. Please bring all your insurance information to your appointment. If you have any questions, call Patient Financial Services at 212-639-3810.

Talk With Your Social Worker About Housing, If Needed

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

For questions about housing, call the Social Work department at 212-639-7020.

Tumor Testing

Depending on the type of tumor you have, you may need testing to see if the antibody will attach itself to the tumor. If the antibody doesn’t attach itself to the tumor, you can’t have intrathecal RIT. Your doctor will discuss this with you.

Intraventricular Access Device

Ommaya Reservoir or Programmable VP Shunt Reservoir

During your treatment, the antibody will be injected directly into either your Ommaya reservoir or a programmable VP shunt reservoir. If you have a nonprogrammable VP shunt, it may be converted to a programmable VP shunt, if possible.

If you need to have an Ommaya reservoir placed or your nonprogrammable VP shunt converted to a programmable VP shunt, your doctor or NP will arrange this for you.

Check the box next to which procedure you will have below:

- Placement of an Ommaya reservoir
  - You will have an Ommaya reservoir placed during a surgery. For more information, read About Your Ommaya Reservoir Placement Surgery for Pediatric Patients.
Conversion of a nonprogrammable VP shunt to a programmable VP shunt

- Your nonprogrammable VP shunt will be converted to a programmable VP shunt during a surgery. For more information about a programmable VP shunt, read About Your Programmable VP Shunt for Pediatric Patients and About Your Ventriculoperitoneal (VP) Shunt Surgery for Pediatric Patients. You can search for these resources on our website www.mskcc.org/pe or ask your nurse.

If you have a programmable VP shunt, write down your shunt type and pressure setting below:

- Type of programmable VP shunt: _________________________
- Pressure setting: _________________________

Your NP will also give you a wallet card to fill out. Carry it with you at all times.

Within 3 Weeks Before Your First Antibody Injection

You will need to have the following exams and tests to make sure that it’s safe for you to have antibody therapy:

- Physical exam
- Neurological exam
- Blood tests to check your blood counts and kidney, liver, and thyroid function
- Pregnancy test for females of childbearing age
- Tests to check for cancer cells in your CSF
- Magnetic resonance imaging (MRIs) of your brain and spine to make sure there is no new or growing disease
- CSF flow study to make sure your Ommaya reservoir or programmable VP shunt reservoir is working correctly
- Neurocognitive function testing, if you're 3 years old or older. This is done to test your thinking, learning, and memory.
- Quality of Life testing, if you're 5 years old or older. This is done to check your overall well-being, feelings, and emotions.

Write down the dates and times of your brain and spine MRIs below:

<table>
<thead>
<tr>
<th>Scan</th>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain MRI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spine MRI</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CSF Flow Study

A CSF flow study is done to make sure that your Ommaya reservoir or programmable VP shunt reservoir is working well. During the flow study, your doctor or NP will inject a radioactive dye into your reservoir. You will have a nuclear medicine scan a few hours later to see how well the dye moves through your CSF. You will have another nuclear medicine scan about 24 hours later, and if necessary, a third scan about 48 hours later.

Write down the dates and times of your CSF Flow Study below:

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSF Flow Study Injection followed by scan</td>
<td></td>
</tr>
<tr>
<td>About 24 Hours after injection</td>
<td></td>
</tr>
<tr>
<td>About 48 Hours after injection</td>
<td></td>
</tr>
</tbody>
</table>

Scans with Anesthesia

If you will need to have anesthesia (medication to make you sleepy) during your scans, your doctor or NP will arrange this for you. You will not be able to eat or drink anything for a certain amount of time before your scans. Your NP will go over these guidelines with you. **If you do not follow these guidelines, your scans may be canceled.**

If you need anesthesia with your scans, write down your eating and drinking guidelines before your scans below:

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

5 to 7 Days Before Your First Antibody Injection

Take Your Potassium Iodide (SSKI®) and Liothyronine (Cytomel®)

You will start taking medications called potassium iodide (SSKI®) and liothyronine (Cytomel®) 5 to 7 days before your first antibody injection. These medications will help protect your thyroid during treatment.

You will take these medications every day until 2 weeks after your last antibody injection. For more information about these medications, read Potassium Iodide and Liothyronine, located in the “Medications” section of this guide.
Follow the guidelines in the table below:

<table>
<thead>
<tr>
<th>Start Date</th>
<th>End Date</th>
<th>Medication</th>
<th>Dose</th>
<th>How Often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Potassium iodide (SSKI®)</td>
<td>7 drops</td>
<td>Once a day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Liothyronine (Cytomel*)</td>
<td>□ 25 mcg (1 tablet) or</td>
<td>Once a day</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>□ 50 mcg (2 tablets)</td>
<td></td>
</tr>
</tbody>
</table>

Your doctor or NP will give you a medication diary. Write down each dose that you take in your medication diary. Be sure to write down any missed doses in your diary. Bring your diary to all your appointments.

Write down any information about taking potassium iodide (SSKI) and liothyronine (Cytomel) below:

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

The Night Before Each Antibody Injection

Take Your Dexamethasone (Decadron®) and Antacid

The night before each antibody injection, you will take a steroid called dexamethasone (Decadron®). This medication is given to control inflammation (swelling and redness).

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

- 1 time the night before each injection
- 2 times in clinic on the day of your injection. Your doctor or nurse will give it to you.
- 2 times the day after each injection
- 1 time the second day after each injection

You will also take an antacid with the dexamethasone. Take the antacid as prescribed by your doctor. For more information, read the “Instructions for Home Medications” section of this guide.

Write down the name of the antacid that you were prescribed below:

__________________________________________________________________________________________________

Refer to the dexamethasone and antacid schedule below for each antibody injection. Remember, you will take a total of 6 doses of dexamethasone for each injection. Two of these doses will be given to you at the Pediatric Ambulatory Care Center (PACC).
Write down the dates and times that you will take the dexamethasone with antacid and the dose below:

<table>
<thead>
<tr>
<th>Dates</th>
<th>Morning</th>
<th>Evening</th>
<th>Steroid: Dexamethasone</th>
<th>Antacid: Name:</th>
<th>Dose:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Night before each antibody injection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day of injection (this dose will be given in the PACC)</td>
<td>Given in the PACC</td>
<td>Given in the PACC</td>
<td>Given by IV</td>
<td>Given by IV</td>
<td></td>
</tr>
<tr>
<td>1st day after injection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd day after injection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The information in this section will tell you what to expect during your treatment, including the procedures you will have and the medications you will take.

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

Notes

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____________________________________________________________________________________________
The Day of Your Treatment

Where to Go

Your appointment 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

Parking at the PACC

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 is a pedestrian 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.

When to Arrive

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

What to Expect

Your antibody injections will be given in the PACC, usually on an outpatient basis. Side effects of your treatment can usually be taken care of in the outpatient clinic. Some people will need to be admitted to the hospital.

You will be given a private room in the PACC. Your doctor or NP will give you a physical exam and a blood test before each injection.

You will need to wait for a few hours between having your blood work done and getting your antibody injection. During this time, you can go on the computer or play in the playroom.
**Ommaya Reservoir Tap**

If you have an Ommaya reservoir, you will have a procedure called an Ommaya reservoir tap done during your antibody injections. You may also have it done during some of your routine check-ups after your antibody therapy is finished. For more information, read *Frequently Asked Questions About Ommaya Reservoirs and Ommaya Taps for Pediatric Patients* located in the “Educational Resources” section of this guide.

Your doctor or NP will do this procedure at your bedside. You don’t need to do anything to prepare for it. During your procedure, you may be asked to lie on your back. Your doctor or NP will clean the skin over the top of your Ommaya reservoir with providone-iodine (Betadine®). Tell your doctor or NP if you’re allergic to iodine and they will use a different solution.

A small needle with tubing attached to it will be inserted into your reservoir. A small amount of your CSF will be taken out through a syringe that is attached to the tubing.

If you’re getting the antibody injection during your tap, your doctor or NP will inject it slowly into your Ommaya reservoir after the sample of your CSF is taken out. This usually doesn’t hurt. Depending on your treatment, you may need to have more samples of your CSF taken after the injection. The needle may be left in your Ommaya reservoir for a few hours after your injection to take these samples.

If you’re having a tap during a routine check-up after your antibody therapy is finished, a sample of your CSF will be taken and the needle will be removed right away.

You don’t need to follow any restrictions after the tap. You can wash your hair as usual.

**Programmable VP Shunt Reservoir Tap**

The procedure for a programmable VP shunt reservoir tap is almost the same as an Ommaya reservoir tap. The only difference is that the shunt is turned off before your antibody injection. It will stay off for about 4 hours after your injection and then changed back to the original setting.

Tell your doctor, nurse, or NP if you have a headache, pain, nausea, or vomiting while your shunt is turned off.

**Test Dose Injection**

Your first antibody injection is called a test dose. Your doctor will inject a small amount of the antibody into your Ommaya reservoir or programmable VP shunt reservoir. After the injection, the tube coming from your Ommaya reservoir or programmable VP shunt reservoir will be carefully taped to your head for several hours. This will let your doctor take samples of your CSF, if needed.

**Before Your Test Dose Injection**

Before your doctor or NP gives you your injection, samples of your blood and CSF will be taken.

You will be given antinausea medication, 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.
After Your Test Dose Injection

**Radiation Safety Precautions**

* Tell us if anyone who is caring for you is pregnant.

Your radiation safety officer will talk with you about what precautions you will need to follow after your test dose.

Write down your radiation safety restrictions:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

1 to 4 hours after your first test dose injection

Samples of your blood and CSF will be taken about every hour for 4 hours after your injection.

This will only be done after your first test dose injection.

1 hour after your test dose injection

About 1 hour after your injection, you will be given an antibiotic medication through an intravenous (IV) line to help prevent infection.

4 hours after your first test dose injection

About 4 hours after your first injection, you will have:

- Your first nuclear medicine scan
- An Ommaya reservoir or programmable VP shunt reservoir tap
- Blood samples taken

This will only be done after your first test dose injection.

Write down the date and time of your first nuclear medicine scan below:

Date: ________________ Time: ________________

Every 4 to 6 hours for 24 hours after your test dose injection

You can take acetaminophen (Tylenol®) every 4 to 6 hours for 24 hours after the injection to prevent fever and pain. You can also take antinausea and pain medications as directed by your doctor. Your NP will go over these medications with you.

For more information about home medications, read the “Instructions for Home Medications” section of this guide.
24 hours after your first test dose injection

Scans and tests
About 24 hours after your first injection, you will have:

- Your second nuclear medicine scan
- An Ommaya reservoir or programmable VP shunt reservoir tap
- Blood samples taken

This will only be done after your first test dose injection.

Write down the date and time of your second nuclear medicine scan below:

Date: ____________________ Time: ____________________

Take your medications

- Continue to take the dexamethasone twice a day with an antacid.
- Continue to take the potassium iodide and liothyronine every day until the end date written in the table on page 8 of this guide.

48 hours after your first test dose injection

Scans and tests
About 48 hours after your first injection, you will have:

- Your third nuclear medicine scan
- An Ommaya reservoir or programmable VP shunt reservoir tap
- Blood samples taken

Write down the date and time of your third nuclear medicine scan below:

Date: ____________________ Time: ____________________

Take your medications

- Take the last dose of dexamethasone with an antacid.
- Continue to take the potassium iodide and liothyronine every day until the end date written in the table on page 8 of this guide.

Treatment Dose Injections

One week after your test dose injection, you will start getting the full antibody dose injections. This is also called the treatment dose. You won’t need to have any blood samples taken, Ommaya or programmable VP shunt reservoir taps, or nuclear medicine scans after the treatment dose injection.
The injections are given in rounds or cycles. The number of rounds you have will depend on your treatment plan. Your doctor will discuss this with you.

**Radiation Safety Precautions**

After you get your treatment dose injection, you will be radioactive for a period of time. You will need to be careful so that people near you have limited radiation exposure. Some of the radiiodine will leave your body through urine (pee) and bodily secretions.

**Tell us if anyone who is caring for you is pregnant or if you’re staying at the Ronald McDonald House.**

Your radiation safety officer will talk with you about what precautions you will need to follow. You will also get written guidelines to follow.

Write down your radiation safety restrictions:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

You will be given a post therapy radiation safety wallet card that will summarize your treatment. Keep this with you at all times. If you need emergency medical care, or if you're stopped by security, show this card.
The information in this section will tell you what to expect after your treatment dose injection.

Write down any questions you have and be sure to ask your doctor or nurse.
During the 2 weeks after your treatment dose injection, you will be seen in the clinic for physical exams and blood tests, usually once a week. If you return home, you will have to be seen by your home oncologist (cancer doctor) for physical exams and blood tests.

2 weeks after your treatment dose injection

You can stop taking the potassium iodide and liothyronine 2 weeks after your treatment dose injection. This end date is written in the table on page 8 of this guide. Ask your doctor or NP to confirm this date with you.

Complete your Medication Diary, sign it, and give it to your doctor or NP.

3 weeks after your treatment dose injection

About 3 weeks after your treatment dose injection, you will have:

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

Write down the date and time of your MRI scans below:

<table>
<thead>
<tr>
<th>Scan</th>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain MRI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spine MRI</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Follow-up Care

After your antibody therapy is finished, you will have a follow-up appointment with your doctor and NP.

Write down the date and time of your follow-up appointment below:

Date: ____________________ Time: ____________________

You will have neurocognitive function and Quality of Life testing done 3 months after your last treatment dose, then once a year after that.

Write down the date and time of your neurocognitive function and Quality of Life testing appointment below:

Date: ____________________ Time: ____________________
Call Your Doctor or NP Right Away if You Have:

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

Contact Information

If you have any questions or concerns, please talk with your doctor 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, please 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.
The information in this section contains important information about what medications you will take before and after your treatment. Read through this section before your treatment so that you’re prepared.

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

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Medication Diary

Your doctor or NP will give you a medication diary to record the potassium iodide (SSKI) and liothyronine (Cytomel) you take. Please write your initials in each box when you take your medication. Be sure to write down any missed doses in your diary. Bring your diary to all your appointments.

Instructions for Home Medications

Before Your Injections

- **Dexamethasone (Decadron®)**
  - Instructions: Take ________ mg by mouth twice a day, starting the night before your injection. Follow the instructions given on page 7 for the rest of your doses. On the days of injection, you will receive this medication in the PACC.

- **Ranitidine (Zantac®)**
  - Instructions: Take ________ mg by mouth twice a day on the days when you take the dexamethasone. On the days of injection, you will receive this medication in the PACC.

- **Hydromorphone (Dilaudid®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for headache or pain.

- **Hydroxyzine (Vistaril®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for nausea or vomiting.

- **Lorazepam (Ativan®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for nausea, vomiting, or agitation.

After Your Injections

- **Hydromorphone (Dilaudid®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for headache or pain.

- **Hydroxyzine (Vistaril®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for nausea or vomiting.

- **Lorazepam (Ativan®)**
  - Instructions: Take ________ mg by mouth every 4 to 6 hours if needed for nausea, vomiting, or agitation.
• **Ondansetron (Zofran®)**
  - Instructions: Take ______ mg by mouth every 8 hours if needed for nausea or vomiting. On days of injection, you will receive this medication in the PACC.

• **Acetaminophen (Tylenol®)**
  - Instructions: Take ______ mg by mouth every 4 to 6 hours for 24 hours after the injection and then every 6 hours as needed for headache or body aches.

Remember to take the potassium iodide (SSKI) and liothyronine (Cytomel®) every day until the end date your doctor gave you. Your end date is on page 8 of this guide. Please refer to your Medication Diary for more information.
Potassium Iodide

Brand Names: US
iOSAT [OTC]; SSKI; ThyroSafe [OTC]; ThyroShield [OTC] [DSC]

What is this drug used for?

- It is used to prevent thyroid cancer from radiation.
- It is used to thin mucus so it can be taken from the body by coughing.
- It is used to aid diet needs.
- It may be given to your child for other reasons. Talk with the doctor.

What do I need to tell the doctor BEFORE my child takes this drug?

- If your child has an allergy to this drug or any part of this drug.
- If your child has an allergy to iodine.
- If your child is allergic to any drugs like this one or any other drugs, foods, or other substances. Tell the doctor about the allergy and what signs your child had, like rash; hives; itching; shortness of breath; wheezing; cough; swelling of face, lips, tongue, or throat; or any other signs.
- If your child has any of these health problems: Certain skin or blood vessel problems.
- If your child has a growth on the thyroid gland and has heart disease.

This is not a list of all drugs or health problems that interact with this drug.

Tell the doctor and pharmacist about all of your child’s drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe for your child to take this drug with all of his/her drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking
What are some things I need to know or do while my child takes this drug?

- Tell all of your child’s health care providers that your child is taking this drug. This includes your child’s doctors, nurses, pharmacists, and dentists.
- Have your child’s blood work checked often. Talk with your child’s doctor.
- This drug may affect certain lab tests. Tell all of your child’s health care providers and lab workers that your child takes this drug.
- Talk with the doctor before your child uses a salt substitute.
- Give this drug only as you have been told by the doctor. Do not give more than you were told to give or give more often then you were told to give it. Giving too much of this drug may raise the risk of side effects. Do not give this drug if your child is allergic to iodine.

If your child is pregnant or breast-feeding a baby:

- This drug may cause harm to the unborn baby if your child takes it during pregnancy. If your child is pregnant or gets pregnant while taking this drug, call the doctor right away.
- Tell the doctor if your child is breast-feeding a baby. You will need to talk about any risks to the baby.
- If your child is taking this drug and is breast-feeding a baby, have the baby’s thyroid checked.

What are some side effects that I need to call my child’s doctor about right away?

**WARNING/CAUTION:** Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child’s doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or
swelling of the mouth, face, lips, tongue, or throat.

- Trouble swallowing or speaking.
- Wheezing or coughing.
- Shortness of breath.
- A heartbeat that does not feel normal.
- Chest pain.
- Fever and joint pain.
- Neck swelling.
- Swelling in the arms or legs.
- Feeling of heaviness in your arms or legs.
- Black, tarry, or bloody stools.
- Throwing up blood or throw up that looks like coffee grounds.
- A burning, numbness, or tingling feeling that is not normal.
- Feeling very tired or weak.
- Feeling confused.
- Very bad headache, metal taste, sore teeth and gums, burning of the mouth or throat, eye irritation, eyelid swelling, more spit, or skin irritation.

**What are some other side effects of this drug?**

*All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child’s doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:*

- Headache.
- Upset stomach or throwing up.
- Belly pain.
- Loose stools (diarrhea).

*These are not all of the side effects that may occur. If you have questions about side effects, call your child’s doctor. Call your child’s doctor for medical advice about side effects.*
You may report side effects to your national health agency.

**How is this drug best given?**
*Give this drug as ordered by your child’s doctor. Read all information given to you. Follow all instructions closely.*

**All liquid products:**

- Measure liquid doses carefully. Use the measuring device that comes with this drug.

**Liquid:**

- Give this drug with food or a milky drink.
- Mix liquid with water, milk, or fruit juice before giving to your child.
- Do not use if it turns brownish-yellow.
- Have your child drink lots of noncaffeine liquids every day unless told to drink less liquid by your child’s doctor.

**Radiation exposure:**

- Give this drug only when told to by public health officials.
- Give once a day until the chance of being exposed to radiation ends.
- You may make a liquid mixture using the tablet. Crush the tablet and mix it with water as told. It is then to be mixed with low fat white or chocolate milk, infant formula, orange juice, flat soda, or raspberry syrup. The mixture may be stored in the refrigerator for up to 7 days.

**What do I do if my child misses a dose?**

- Give a missed dose as soon as you think about it.
- If it is close to the time for your child’s next dose, skip the missed dose and go back to your child’s normal time.
- Do not give 2 doses at the same time or extra doses.

**How do I store and/or throw out this drug?**

**All products:**
• Store at room temperature.
• Store in a dry place. Do not store in a bathroom.
• Protect from light.
• Keep lid tightly closed.
• Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
• Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

All liquid products:

• Protect from cold.

General drug facts

• If your child’s symptoms or health problems do not get better or if they become worse, call your child’s doctor.
• Do not share your child’s drug with others and do not give anyone else’s drug to your child.
• Keep a list of all your child’s drugs (prescription, natural products, vitamins, OTC) with you. Give this list to your child’s doctor.
• Talk with your child’s doctor before giving your child any new drug, including prescription or OTC, natural products, or vitamins.
• Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your child’s doctor, nurse, pharmacist, or other health care provider.
• If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

Consumer Information Use and Disclaimer
This information should not be used to decide whether or not to take this medicine or any other medicine. Only the healthcare provider has the knowledge and training to decide which medicines are right for a specific patient. This information does not endorse any medicine as safe, effective, or approved for treating any patient or health condition. This is only a brief summary of general information about this medicine. It does NOT include all information about the possible uses, directions, warnings, precautions, interactions, adverse effects, or risks that may apply to this medicine. This information is not specific medical advice and does not replace information you receive from the healthcare provider. You must talk with the healthcare provider for complete information about the risks and benefits of using this medicine.

Last Reviewed Date
2017-11-28

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Liothyronine

Brand Names: US
Cytomel; Triostat

Brand Names: Canada
Cytomel

Warning

- Do not give this drug to treat obesity or for weight loss. Very bad and sometimes deadly side effects may happen with this drug if it is taken in large doses or with other drugs for weight loss. Talk with the doctor.

What is this drug used for?

- It is used to add thyroid hormone to the body.
- It may be given to your child for other reasons. Talk with the doctor.

What do I need to tell the doctor BEFORE my child takes this drug?

- If your child has an allergy to this drug or any part of this drug.
- If your child is allergic to any drugs like this one or any other drugs, foods, or other substances. Tell the doctor about the allergy and what signs your child had, like rash; hives; itching; shortness of breath; wheezing; cough; swelling of face, lips, tongue, or throat; or any other signs.
- If your child has any of these health problems: Overactive thyroid gland or weak adrenal gland.

*This is not a list of all drugs or health problems that interact with this drug.*

*Tell the doctor and pharmacist about all of your child’s drugs (prescription or OTC,*
natural products, vitamins) and health problems. You must check to make sure that it is safe for your child to take this drug with all of his/her drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking with the doctor.

What are some things I need to know or do while my child takes this drug?

All products:

- Tell all of your child’s health care providers that your child is taking this drug. This includes your child’s doctors, nurses, pharmacists, and dentists.
- Do not run out of this drug.
- If your child has high blood sugar (diabetes), you will need to watch his/her blood sugar closely.
- Have blood work checked as you have been told by the doctor. Talk with the doctor.
- This drug may affect how much of some other drugs are in the body. If your child is taking other drugs, talk with the doctor. Your child may need to have blood work checked more closely while taking this drug with other drugs.

If your child is pregnant or breast-feeding a baby:

- Talk with the doctor if your child is pregnant, becomes pregnant, or is breast-feeding a baby. You will need to talk about the benefits and risks of using this drug.

Injection:

- This drug is not approved for use in children. Talk with the doctor.

What are some side effects that I need to call my child’s doctor about right away?

**WARNING/CAUTION:** Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child’s doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:
• Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat.

• Signs of a weak adrenal gland like a very bad upset stomach or throwing up, very bad dizziness or passing out, muscle weakness, feeling very tired, mood changes, not hungry, or weight loss.

• Signs of high blood sugar like confusion, feeling sleepy, more thirst, more hungry, passing urine more often, flushing, fast breathing, or breath that smells like fruit.

• Chest pain or pressure or a fast heartbeat.

• A heartbeat that does not feel normal.

• Headache.

• Bothered by heat.

• Sweating a lot.

• Feeling irritable.

• Shortness of breath, a big weight gain, or swelling in the arms or legs.

If your child has menstrual periods:

• Period (menstrual) changes.

What are some other side effects of this drug?

*All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child’s doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:*

• Hair loss may happen in some people in the first few months of using this drug. This most often goes back to normal.

*These are not all of the side effects that may occur. If you have questions about side effects, call your child’s doctor. Call your child’s doctor for medical advice about side effects.*

*You may report side effects to your national health agency.*
How is this drug best given?

Give this drug as ordered by your child’s doctor. Read all information given to you. Follow all instructions closely.

Tablet:

- Give this drug at the same time of day.
- If your child takes colesvelam, colestipol, or cholestyramine, talk with the pharmacist about how to give them with this drug.
- It may take several weeks to see the full effects.
- Keep giving this drug to your child as you have been told by your child’s doctor or other health care provider, even if your child feels well.

Injection:

- It is given as a shot into a vein.

What do I do if my child misses a dose?

Tablet:

- Give a missed dose as soon as you think about it.
- If it is close to the time for your child’s next dose, skip the missed dose and go back to your child’s normal time.
- Do not give 2 doses at the same time or extra doses.

Injection:

- Call your child’s doctor to find out what to do.

How do I store and/or throw out this drug?

Tablet:

- Store at room temperature.
- Store in a dry place. Do not store in a bathroom.
- Protect from light.

Injection:
If you need to store this drug at home, talk with your child’s doctor, nurse, or pharmacist about how to store it.

All products:

- Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

General drug facts

- If your child’s symptoms or health problems do not get better or if they become worse, call your child’s doctor.
- Do not share your child’s drug with others and do not give anyone else’s drug to your child.
- Keep a list of all your child’s drugs (prescription, natural products, vitamins, OTC) with you. Give this list to your child’s doctor.
- Talk with your child’s doctor before giving your child any new drug, including prescription or OTC, natural products, or vitamins.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your child’s doctor, nurse, pharmacist, or other health care provider.
- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

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precautions, interactions, adverse effects, or risks that may apply to this medicine. This information is not specific medical advice and does not replace information you receive from the healthcare provider. You must talk with the healthcare provider for complete information about the risks and benefits of using this medicine.

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This section includes a list of MSK support services, as well as the resources that were referred to throughout this guide. These resources will help you prepare for your surgery and recover safely.

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

Notes
Frequently Asked Questions About Ommaya Reservoirs and Ommaya Taps for Pediatric Patients

This information answers some commonly asked questions about Ommaya reservoirs and Ommaya taps. In this resource, the words “you” and “your” refer to you or your child.

Ommaya Reservoirs

What is an Ommaya reservoir?

An Ommaya reservoir is a quarter-sized, soft, plastic, dome-shaped device that is placed under the scalp. It’s connected to a catheter (thin, flexible tube) that’s placed in one of the ventricles in your brain (see Figures 1 and 2). Your ventricles are hollow spaces that make cerebrospinal fluid (CSF), which
surrounds your brain and spinal cord.

**Why do I need an Ommaya reservoir?**

An Ommaya reservoir will help your healthcare provider:

- Get samples of your CSF. Your healthcare provider can check your CSF for cancer cells or infections.
- Give you medication, such as chemotherapy, monoclonal antibodies, or antibiotics directly into your CSF.

These procedures are referred to as an “Ommaya reservoir tap.” You may need fewer spinal taps, if you have an Ommaya reservoir.

**How is an Ommaya reservoir placed?**

Your Ommaya reservoir will be placed during a surgery. Your doctor or nurse will explain the details of your surgery. Your nurse will help you prepare and will give you a resource called *About Your Ommaya Reservoir Placement Surgery for Pediatric Patients* (mskcc.org/pe/ommaya_reservoir_surgery). You can also search for the resource at www.mskcc.org/pe

**Can the Ommaya reservoir be removed?**

The reservoir usually isn’t removed unless you have complications with it.

**Are there restrictions on my activities with an Ommaya reservoir?**

For at least 2 to 6 weeks after your Ommaya reservoir placement surgery, don’t participate in any contact sports (such as football, boxing, or wrestling). This gives your incision (surgical cut) time to heal.

Talk with your neurosurgeon about when you can resume gym class and contact sports again. Remember to wear a helmet, if needed. This reduces your risk of getting a head injury.

**How do I care for my Ommaya reservoir?**

Your Ommaya reservoir doesn’t need special care. You can wash your hair as usual.
About Ommaya Reservoir Taps

Do I need to do anything to prepare for my Ommaya reservoir tap?

Tell your healthcare provider if you’re allergic to iodine (Betadine®). They will use a different solution.

You don’t need to do anything else to prepare for your tap. You can eat your meals and take your medications as usual.

Some people may have another scan or procedure after the tap. If you will be getting anesthesia (medication to make you sleepy), follow the directions that healthcare provider gave you about eating, drinking, and taking medications.

What happens during the tap?

Your healthcare provider will perform your tap in an exam room or at your bedside.

1. Your healthcare provider will gently feel the Ommaya reservoir. They will push down on it several times to pump it. This pulls the CSF into the reservoir.

2. You may be asked to lie on your back. Your healthcare provider will clean your skin with Betadine or a different solution if you’re allergic to Betadine.

3. Your healthcare provider will insert a small needle with tubing attached to it into your reservoir (see Figure 3). You might feel slight discomfort from the needlestick. Your healthcare provider will take out a small amount of CSF through a syringe that’s attached to the tubing. The CSF may be sent to the lab to check for cancer cells or infection. If you’re also getting medication during the tap, some of the CSF may be saved in the syringe to be used as a “flush” (see step 4).
4. If you’re getting medication during the tap, your healthcare provider will inject it slowly into your reservoir, after withdrawing the CSF. They will then flush your Ommaya reservoir with the saved CSF to push the medication into your ventricle.

5. Your healthcare provider will remove the needle and apply gentle pressure with gauze for about 1 minute to prevent any CSF from leaking out. The area may then be covered with a bandage (Band-Aid®).

**How long does the tap take?**
The tap usually takes about 15 minutes.

**When can I resume my normal activities?**
You can resume all your normal activities after your tap, including washing your hair. Your Ommaya reservoir won’t need any special care.

**Call Your Healthcare Provider if You Have:**

- A temperature of 100.4° F (38° C) or higher
- Tenderness, redness, or swelling around your reservoir
- Clear, bloody, or pus-like discharge from your reservoir
- Headaches
- Vomiting
- Neck stiffness
- Blurry vision
- Confusion
MSK Resources

Anesthesia
212-639-6840
Call if you have any questions about anesthesia.

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 the main lobby of Memorial Hospital 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.

Integrative Medicine Service
646-888-0800
Integrative Medicine Service offers many services to complement (go along with) traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy.

Patient and Caregiver Support Program
212-639-5007
You may find it comforting to speak with a cancer survivor or caregiver who has been through a similar treatment. Through our Patient and Caregiver Support Program, you’re able to speak with former patients and caregivers.

Patient Billing
646-227-3378
Call if you have any 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.

Social Work
212-639-7020
Social workers help patients, family, and friends deal with issues that are common for cancer patients. 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.

For additional online information, visit LIBGUIDES on MSK’s library website at http://library.mskcc.org. You can also contact the library reference staff at 212-639-7439 for help.

External Resources

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 can’t 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.

CancerCare
www.cancercare.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 people 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.

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
http://lgbtcancer.com/
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.