I-131 MIBG Treatment

A Guide for Parents and Caregivers
Introduction

• This information is for parents or family members who are providing care for their children for treatment of neuroblastoma or pheochromocytoma with I-131 MIBG (Metaiodobenzylguanidine).

• Any parent or family member who will give care during the treatment must read this information. The law requires that at least one parent or caregiver must be available at all times to help with daily care during treatment.

• Please print, sign and date page 59 of this document to confirm that you have seen this training and understand it. Talk to your child’s provider if you have any questions. If you do not have a printer, you can print in the Family Resource Center.
Section 1: What is I-131 MIBG? How does it fight cancer?
What is I-131 MIBG?

MIBG is short for Metaiodobenzylguanidine and is used to treat neuroblastoma or pheochromocytoma. It does this by bringing radiation to your child’s tumors. It is a clear liquid that looks like water.
How does it fight cancer?

- MIBG travels right to the tumors.
- I-131 is a kind of radioactive iodine. When it is attached to MIBG to make I-131 MIBG, it brings radiation to the tumors.
What is different about I-131 MIBG treatment compared to other treatments?

- Radiation is a powerful tool against cancers. Normal healthy tissue can also be harmed by high doses of radiation.
- Because I-131 MIBG gives off radiation, the government strictly regulates how it can be used.
- Hospitals have to be able to control the radiation from this treatment. This involves special equipment, and not all hospitals have this. Also, hospital staff need special training. The providers who will care for your child have this training.
I-131 MIBG Treatment

- I-131 MIBG is only available through a clinical trial or through a compassionate use protocol. Compassionate use protocols can sometimes allow patients to get treatments that are not usually available, even if they are not in a clinical trial.

- I-131 MIBG therapy is only available at hospitals approved to use I-131 MIBG. Patients must stay in the hospital to get it.

- The average hospital stay is 5 to 7 days, but could be longer. Your child will have to come to Seattle Children’s Hospital at least 2 days before treatment begins.

- One non-pregnant parent or caregiver must be available at all times to help with daily care.

- Your child’s medical team will explain exactly how they will give the I-131 MIBG treatment and what parents and family members need to do.
Why does my child need to stay in the hospital?

• Your child will get treatment through an IV. It enters the bloodstream, where it will go to the cancer cells.

• Once the treatment brings radiation to the tumors ("attacks" them), it leaves your child’s body through their pee (urine) over the next several days. It also leaves through saliva (spit), sweat and through bowel movements.

• This means that bodily wastes are radioactive for a period of time. The hospital has the training and equipment to make sure that other people do not get exposed to high levels of radiation.
Why does my child need to stay in the hospital?

• Federal laws require that patients who get higher doses of radiation must stay in the hospital until they do not have high levels of radiation in their body. The laws also restrict what patients can do while they are in the hospital.

• Your child can leave the hospital when the levels of radiation in their body are safe for other people to be around.

• Once your child is released from the hospital, there are no federal restrictions on what you or your child can do. But we will provide you with guidelines to stay safe after leaving the hospital and to avoid unwanted radiation exposures.
Section 2: What is involved in I-131 MIBG treatment?
What are the steps before the treatment?

• First, your child will get a non-radioactive form of iodine. This is called Potassium Iodine. It helps to protect your child’s thyroid gland from being harmed by radiation. Your child will take this 1 day before and for 6 weeks after I-131 MIBG treatment. Your child may need a nasogastric tube (a tube that goes through the nose to help with eating) for the first week of Potassium Iodine therapy.

• Your child will need an IV to receive the I-131 MIBG treatment. If your child does not have a central line, they will need to get an IV put in the day before the treatment.

• During the week before the I-131 MIBG treatment, it is important that your child avoids medicines that make I-131 MIBG less effective. This includes common cold medicines. We will give you a list of medicines to avoid.

• Because urine will be radioactive, it is important that your child not pee into the toilet or diapers. Your child will need a Foley (urinary) catheter to drain the bladder. This may be put in under anesthesia or sedation (medicine to help your child relax and not have pain) the day before I-131 MIBG treatment.
Where does the I-131 MIBG come from?

I-131 MIBG for this treatment is made by a pharmaceutical company located in Canada. They ship the frozen I-131 MIBG to Seattle.
How does my child’s care team give I-131 MIBG?

• The frozen I-131 MIBG is thawed.
• A radiopharmacist puts the thawed I-131 MIBG in a large syringe.
• The I-131 MIBG will be given from this syringe through your child’s IV tube.
Who will give my child the I-131 MIBG?

• The nursing staff will get your child ready for the infusion.
• The nuclear medicine technologist will give the I-131 MIBG using the infusion pump.
• It usually takes about 2 hours to give the I-131 MIBG.
• A nuclear medicine doctor and an attending hematology/oncology (hem/onc) doctor will be available during the infusion.
Treatment Side Effects

Your child’s care team will try to keep your child from having any side effects. But it is possible that your child may have:

• Nausea and throwing up (vomiting): This usually happens in the first 24 to 48 hours after the infusion. Your child’s care team will give your child medicines to try to prevent this.

• Short-term loss of appetite

• Jaw pain and/or dry mouth

• Discomfort from the urinary Foley catheter

• Some side effects may happen later on, like low blood counts. These are discussed in the section about follow-up care.
Section 3: Getting Ready for Treatment
How does this treatment affect caregivers?

• All caregivers, including parents, must follow strict rules during this treatment to limit their exposure to radiation.

• Many safeguards will be in place, like wearing protective clothing and having your child stay in a special lead-lined room.

• The caretaker must limit direct physical contact with your child during this treatment and will sleep in a separate room from your child.
What can I expect about my child’s room?

• Your child will stay in a special room with lead-lined doors and walls to block radiation from others.

• A moveable lead shield is next to the bed. When in the room, caregivers should stay behind the lead shield whenever possible.
What can I expect about my child’s room?

• A lead box is near the bed to hold and shield your child’s urine collection bag (Foley bag).
• A urine pump takes the urine from this box to a special drain in the wall.
My Child’s Room: Radiation monitoring

• There is a radiation meter in your child’s room. This meter will always be telling your child’s care team how much radiation your child is giving off.

• The radiation safety officer checks these levels daily.
My Child’s Room: AV monitoring

Parents and caregivers are able to watch and talk to your child. Your child can also see and talk to you.
Prepared Patient Room

All surfaces will be wrapped.
Prepared Patient Room - Bathroom
Patient’s Room: Linen and trash

There are separate waste containers for food, paper, and linen.
Patient’s Room

Everything your child touches will be wrapped in plastic.
Section 4: Making the Best of Your Hospital Time
What can we bring to the hospital?

Radiation contamination can happen if body fluids (skin, sweat, saliva, urine, stool) touch you. This can happen from body-to-body contact or if these fluids get on something else and then you touch them. Anything that your child’s body fluids touch may become contaminated. For this reason:

• Bring ONLY things that your child needs for care and entertainment into the room.
• NOTHING (except glasses and hearing aids) can leave the radiation isolation room without being screened by the radiation safety officer. If an object is contaminated, it must be thrown out or must stay in the hospital for 3-6 months or until it is no longer radioactive.
• Things like personal cell phones or laptops can easily become contaminated. It is best to avoid bringing these into the room, since the care team will need to take them away or store them for a long time if they get contaminated.
• Your luggage and belongings should stay in the parent’s or caregiver’s room, not in your child’s room.
Things to Bring: Comfort and entertainment

- Any special snacks or drinks
- Movies or video games
- Activities your child can do by themselves, such as books and magazines, coloring books, craft supplies, cards (Remember, all of these will be thrown away at the end of your hospital stay.)
- Disposable room decorations to make your child feel comfortable
- Disposable pictures of family, friends, pets, places
- Disposable substitutes for a favorite stuffed animal or comfort item
What can my child do during treatment?

- Your child must remain in bed during the treatment. They may not leave or walk around their room.
- Child Life specialists will help parents plan entertainment and activities for your child both before and during the time they are in the hospital.
What can my child do during treatment?

- Homework: Any paper that your child handles will get contaminated. Make arrangements with your child’s teachers regarding homework before their hospital stay.
- There will be a smart TV with access to the internet in your child’s room.
- Parents or caregivers should make sure that your child avoids touching things in the room.
Section 5: Caregiver Safety Procedures
What are the restrictions for parents/caregivers?

• Only one non-pregnant caregiver will be allowed in your child’s room at any time to provide care and/or comfort.

• Parents and caregivers should avoid unnecessary exposure.

• **Distance is important.** Spend as much time as you can at safe distances from your child, either at the doorway or behind the lead shield in the room.

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Parent and Caregiver “Do’s” and Don’ts”

- Follow radiation safety precautions.
- No caregiver can be pregnant or breastfeeding.
- If you are breastfeeding, talk to your child’s care team and the Radiation Safety Officer for guidance before your child starts therapy.
- Wear long pants. No dresses, shorts or capris.
- Shoes must cover the entire foot. No sandals or flip-flops.
- Wear additional protective clothing that your child’s care team will give to you.
- Wear the radiation dosimeter that your child’s care team gives to you.
Parent and Caregiver “Do’s” and Don’ts”

Parents and caregivers must not:

• Hold your child
• Sleep in your child’s room
• Eat or drink in your child’s room
• Use your child’s bathroom for your own personal care
Parent and Caregiver “Do’s” and Don’ts”

• Your child’s care team will expect you to help care for your child. This may include helping them to take medicines, vital signs, changing diapers and helping with eating or other necessary activities.

• But you should spend most of your time outside of your child’s room.

• If you need to stay in your child’s room for a longer period of time, stay as far away from your child as possible and always behind the lead shield.
The Parent’s or Caregiver’s Room: What can I expect?

- Caregivers will stay in a family room which will have a sleep chair or bed.
- This room will be located next to your child’s room.
Will I be exposed to radiation?

• Yes, you will be exposed to radiation during the treatment.
• Your radiation exposure will be monitored.
• You will keep your radiation exposure as low as possible by following the guidelines and instructions that your child’s care team gives you.
How much radiation exposure will I receive?

- Family caregivers usually receive between 50 and 300 mrem (milirem) during their child’s I-131 MIBG treatment. The federal government limits a family caregiver to 2000 mrem per year. The limit for medical staff is 5000 mrem per year.

- By comparison, a person living in the USA receives a “natural” background radiation dose of about 360 mrem per year.

- The graphs on the next page compare radiation doses received during common tasks of daily living to those received during medical imaging and treatment procedures.
How much radiation exposure will I receive?

Annual background radiation in Seattle (310 mrem)
How much radiation exposure will I receive?

- Drinking 1 cup of milk per day for a year: 0 rem
- Roundtrip flight Seattle to Orlando: 0 rem
- Annual background radiation in Seattle: 0.5 rem
- Annual background radiation in Denver: 0.5 rem
- Annual limit to radiation workers: 10 rem
- Mission to the International Space Station: 100 mSv (millisieverts)
Radiation Safety Training

• Before treatment begins, the radiation safety officer and the nursing staff will train all parents and caregivers about radiation safety.

• It is essential for everyone’s safety that parents, caregivers and patients follow all rules. This ensures:
  • Everyone’s safety
  • That your child will be able to get the carefully timed MIBG treatments as scheduled.
Radiation Safety Training

- Radiation signs will be posted to remind parents and caregivers of radiation risk.
- A barrier will be placed at the edge of the hallway to keep other patients and non-caregivers away from your child’s room.
- If in doubt, ask the staff for help before going into or leaving your child’s room.
Parent and Caregiver Protections:  
Before entering your child’s room

- All parents and caregivers must put on protective clothing before going into your child’s room. Supplies will be located near the entrance to the room. Your child’s care team will teach you how to do this.
- Supplies include:
  - Gown
  - Dosimeter
  - 2 pairs of gloves
  - Shoe covers over shoes (booties)
  - Face mask if needed
- Always step into the patient’s room with booties on!
Radiation Monitoring Devices

• Parents and caregivers are given their own electronic radiation monitoring device, called a “dosimeter.”
• You must wear it at all times while in your child’s room.
• This device measures the parent’s or caregiver’s radiation exposure during your child’s stay in the hospital.
• The radiation staff will teach you how to use this device.
• Make sure you wear the dosimeter on the outside of your protective gown.
Leaving my child’s room:
What will I have to do?

- After taking off all of your protective gear, check yourself for contamination.
- A radiation survey meter is outside of your child’s room to check your hands and feet for radioactive contamination. Your child’s care team will show you how to do this.
- The meter tells you whether you have any radioactive material on you.
- Most likely, any contamination will be on your hands and shoes.
What if the meter detects contamination on my hands?

• Stay in the “clean area” of your child’s room, without touching anything, and wash your hands with soap in the sink.

• After that, check your hands with the radiation detector again and watch the needle on the meter.

• Repeat this process until the needle on the detector does not move all the way to the right when you check your hands.
Why do I have to follow radiation precautions?

• By following the precautions outlined:
  • You will keep your radiation exposure dose as low as possible.
  • You will keep the radiation dose to others low by not spreading contamination.
• If you do not follow the required radiation safety procedures the hospital may not be able to give this treatment any longer.
Section 6: After Treatment
When can my child go home?

• It is required that patients treated with I-131 MIBG therapy stay in the hospital until their radiation level is below a specific level. Your child’s care team will check this level daily.

• Usually, the hospital stay is 5 to 7 days but could be longer.

• When your child leaves the hospital, they will still be giving off radiation.

• Your child’s care team will give instructions about safety and steps that your child needs to follow after leaving the hospital (hygiene, etc.). Everyone needs to carefully follow these instructions.
Guidelines and Precautions for Home Care

• Continue potassium iodide as instructed for 6 weeks after I-131 MIBG therapy.

• For the first 7 days after discharge:
  • Your child should avoid close physical contact (closer than arm’s length) with others, especially pregnant women and young children.
  • Avoid close contact with your child whenever possible for the first week after treatment. For example, avoid napping, cuddling, or sleeping with your child. Avoid kissing them or holding them on your lap for longer than 15 minutes per day.

• Your child should stay out of daycare or school for a week after leaving the hospital.
Guidelines and Precautions for Home Care

• To keep radiation exposure low, you and your child should use good hygiene habits:
  • Flush toilet twice. (Males should sit down to urinate. This helps to avoid splashing.)
  • Take a shower daily.
  • Use disposable gloves whenever you will come in contact with your child’s bodily fluids (urine, saliva, vomit, bowel movements).
  • Wash hands often with soap and water (especially after changing diapers, handling urine, vomit, or bowel movements – even if you wore gloves).
Guidelines and Precautions for Home Care

• Use disposable diapers and place them in an outdoor garbage can daily.

• Use separate eating utensils and avoid sharing personal items such as combs, toothbrushes, etc.

• Your child should use separate towels and washcloths. Wash their bath towels, bed linens, and clothing separately.

• If your child needs outside medical or dental care, tell all medical personnel about these instructions.
Who can I contact if I have questions?

• Drs. Julie Park, Navin Pinto or one of the Neuroblastoma treatment team members: 206-987-2106
• Barb Michieli, Radiation Safety Officer
Certificate of Completion

This is to certify that

Name ________________________________

has completed the
I-131 MIBG Parent/Caregiver Education Course.

Signature ________________________________

Date ________________________________

Please bring a copy of this page with you to your appointment.
Overview of I-131 MIBG Terms

- Radiation: In this case, it is a shortened term for “ionizing radiation” and is used to describe the wave or particle emitted or “given off” by a substance. I-131 is the part of I-131 MIBG that emits radiation. I-131 emits both gamma (wave) and beta radiation (particle).

The radiation emitted or given off by I-131 MIBG is known as ionizing radiation. Ionizing radiation is tasteless, colorless and odorless. I-131 MIBG emits two types of ionizing radiation (gamma radiation and beta radiation). For more information on ionizing radiation, see http://hps.org/publicinformation /radfactsheets/
Terms (continued)

• Radioactive: A term used to describe a substance that emits or “gives off” radiation. I-131 is radioactive.

• Radioisotope: A radioactive substance. In this case, I-131 is the radioisotope.

• Half-life: As radioisotopes emit radiation, they “decay” or become weaker. The half-life is the amount of time it takes for a radioisotope to decay, thereby emitting only half as much radiation. The half-life of I-131 is 8 days. Other radioisotopes have half-lives that range from seconds to many years.

• mrem (millirem) and uSv (microSievert): Units of radiation dose.
Terms (continued)

• Dosimeter: A small device worn near the collar that is used to measure the radiation dose. You can compare this to how an odometer in a car measures miles.

• Radiation meter: An electronic device used to detect the presence of radiation and measure radiation levels.
• Contamination: The presence of a radioisotope (I-131) in an undesired area – for example, on the soles of shoes or in the hallway outside the room. Contamination in this case is the presence of I-131 anywhere but in your child’s body or in the toilet (where urine is disposed of).

• Lead shield: Used to stop gamma radiation. Since lead shields are very thick and lead is a very dense material, it stops or “absorbs” almost all of the gamma radiation from I-131.
Free Interpreter Services

- In the hospital, ask your child’s nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.