



Patient Guide to  
<sup>131</sup>I-MIBG Therapy

**UW**Health  
American Family  
Children's Hospital



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# Table of Contents

Introduction .....	2
Glossary of Terms.....	3
Pre-Treatment Site Visit .....	4
What is Radiation?.....	4
How Can I Be Exposed to Radiation?.....	4
What is <sup>131</sup> I-MIBG? .....	4
Your Child’s Hospital Room .....	5
Child Life .....	6
Caregiver Sleep Room.....	6
Caregiver Responsibilities .....	6-7
Measuring Radiation in Your Child’s Room.....	7
<sup>131</sup> I-MIBG Treatment.....	7-9
Life at Home: What to Know After Leaving the Hospital .....	9-10
Contact Information.....	11

## Introduction

Having a child who has cancer is very stressful for the entire family. It can be extra stressful when you have a child who needs <sup>131</sup>I-MIBG since your child will need special care during this time. This booklet was made to help you understand what <sup>131</sup>I-MIBG therapy is, because we aren’t just treating your child, we are caring for the whole family!



## Glossary of Terms

**Radiation** - The wave or particle emitted or “given off” by a substance.

**Radioactive** - A substance that emits or “gives off” radiation.

**Radioisotope** - A type of radioactive substance. With MIBG therapy,  $^{131}\text{I}$  is the radioisotope.



**mrem (millirem)** - A unit used to measure the radiation dose for a person.

**Dosimeter** - A small electronic device worn near the collar that is used to measure the radiation dose a person receives.

**Radiation Meter** - An electronic device used to detect the presence of radiation and measure radiation levels.

**Lead Shield** - A very thick and dense material used to stop gamma radiation.

**Contamination** - The presence of a radioisotope ( $^{131}\text{I}$ ) in an undesired area. For example, on the soles of shoes or in the hallway outside the room. For MIBG therapy, this would be anywhere but in your child’s body or in the toilet (where urine is disposed).

**$^{131}\text{I}$ -MIBG** - Metaiodobenzylguanidine (MIBG) is a substance that concentrates in neuroblastoma tumors. A type of radioactive iodine ( $^{131}\text{I}$ ) is chemically attached to the MIBG which then forms  $^{131}\text{I}$ -MIBG.

## Pre-Treatment Site Visit

Before your child's treatment, a nurse coordinator or nurse practitioner will schedule a site visit, where you will meet your child's healthcare team and develop a plan for you and your child. This team includes child life staff, radiation safety experts, doctors, nurse practitioners, nurses, social workers and health psychologists. During the site visit, we will teach you about radiation and how to decrease your level of exposure.

## What is Radiation?

Radiation is used to describe the wave or particle "given off" by a substance. Iodine-131 ( $^{131}\text{I}$ ) is the part of  $^{131}\text{I}$ -MIBG that gives off radiation.

## How Can I Be Exposed to Radiation?

During your child's MIBG treatment, anyone caring for your child will be exposed to some radiation. If you follow the guidelines that we give you, your radiation exposure should be quite low.

## What is $^{131}\text{I}$ -MIBG?

Metaiodobenzylguanidine (MIBG) is a substance that concentrates in neuroblastoma and a few other types of tumors. A type of radioactive iodine ( $^{131}\text{I}$ ) is attached to the MIBG, which then makes  $^{131}\text{I}$ -MIBG. When it is given to patients, it helps the medical team to see where the cancer cells are in the body. If the amount of  $^{131}\text{I}$  is high enough, the  $^{131}\text{I}$ -MIBG can kill cancer cells. Only certain hospitals can provide this kind of treatment.



### FOR KIDS

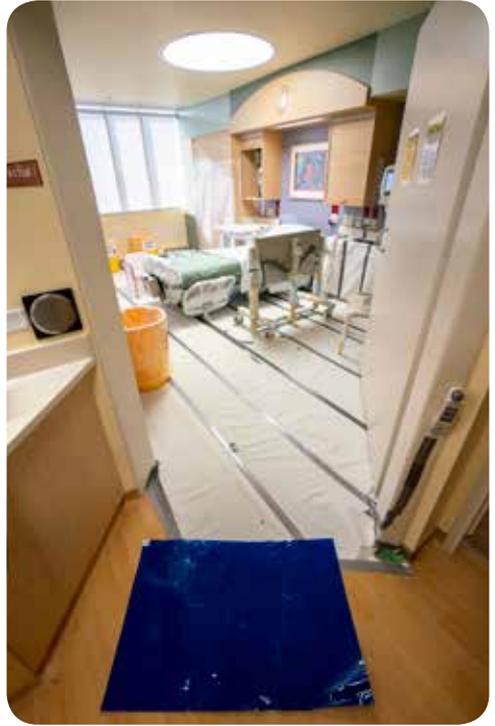
**MIBG is a medicine that looks like water, but it's different than other medicines that you have taken before because it contains radiation.**

# Your Child's Hospital Room

The room used for  $^{131}\text{I}$ -MIBG treatments is a special hospital room that has:

- Lead in the walls, floor and ceiling
- A motorized lead door
- A large mobile lead shield that will be placed between the child's bed and the door
- A lead box at the foot of the bed that will shield the urine bag
- A urine pump
- Special waste containers
- Special equipment, including audio and visual equipment, so your child can interact with you without you being in the room
- The visuals also will be displayed on a monitor at the nurse's station for your child's safety

Most surfaces of the room (floors, bedrails, telephone, etc.) will be covered with plastic and/or paper.



## FOR KIDS

Your hospital room will look just like a typical hospital room, except with plastic and paper on the floor and covering the toilet. Ask the Child Life staff if they can help you decorate your room!

## Child Life

Since items that are brought into the room are at risk for becoming contaminated by radiation, we recommend you do not bring items from home. Our Child Life team will work closely with your child to ensure they have items (iPad, toys, books, etc.) to keep occupied.



## Caregiver Sleep Room

There is a caregiver sleep room next to your child's room that has an audio and video monitoring system that will allow you to see your child and talk to them, without being in your child's room.

## Caregiver Responsibilities

One adult caregiver must be able to help your child take medicine, eat and assist with other necessary activities for the entire hospital stay, including overnight. The caregiver cannot be pregnant. We suggest that you limit the amount of time spent in your child's room as much as you can to decrease your radiation exposure. If you



need to stay in your child's room for a long time, you should sit as far away as possible from your child and behind the lead shield.

While you are in the room:

- No eating or drinking.
- Wear protective clothing (gloves, gown and shoe covers).
- You must wear long pants (e.g., no dresses, shorts, or capri pants) and shoes that cover your entire foot (e.g. no flip flops).

### HELPFUL TIP FOR PARENTS

**Bring books, a laptop/iPad, writing pads and other things to fill your time in the caregiver sleep room.**

- Follow other radiation safety guidelines.
- Wear an electronic pocket dosimeter.
- Do not use the toilet or shower in the room.
- Turn on the Foley pump every 4 hours and let it run for about 15 minutes to empty the urine bag. You will then flush the toilet 5 times to dilute the urine and flush it out of the hospital.
- Any items that go into the room cannot come out of the room until radiation safety staff scans and clears them. Keep all personal items in the caregiver sleep room.

### **HELPFUL TIP FOR PARENTS**

**How well you follow the recommended guidelines will greatly affect the radiation dose you receive. Following these guidelines helps keep your exposure as low as possible.**

## Measuring Radiation in Your Child's Room

A radiation meter is mounted in your child's room. This meter will tell us how much radiation your child is emitting. Each day, radiation safety staff will check levels in the room, taking a measurement one meter (3 feet) from your child's belly button. The radiation levels are monitored on a computer outside your child's room.

## <sup>131</sup>I-MIBG Treatment

Your child will be admitted to American Family Children's Hospital on the P4 unit the day before <sup>131</sup>I-MIBG treatment so they can get used to the <sup>131</sup>I-MIBG room and become familiar with the staff.

### **Before Infusion**

- Your child will need to take SSKI (potassium iodide drops) or Lugol's solution to protect their thyroid from the radiation. Your child will keep taking this medication for about six weeks after discharge.



- Your child will have a Foley catheter placed (depending on the age of your child, we may use sedation to insert the Foley catheter) before the MIBG dose is given to help get rid of the radiation that is in your child's body and protect their bladder.
- A cart will be brought into the room before the treatment begins. An infusion pump will be on the cart and will be surrounded by a lead shield.
- The nursing staff will take your child's vital signs.
- A nuclear medicine technologist will give the  $^{131}\text{I}$ -MIBG infusion.
- A nuclear medicine physician and pediatric oncologist are available during the infusion, if needed.

### During Infusion

- The  $^{131}\text{I}$ -MIBG is infused over 1½ - 2 hours through your child's central line (e.g., PICC Line, Hickman/Broviac).
- Your child will have vital signs checked throughout the infusion.
- The  $^{131}\text{I}$ -MIBG will enter your child's blood stream and then begin to build up in the neuroblastoma tumor cells.



### After Infusion

- Over the next several days, while in the hospital, most of the remaining  $^{131}\text{I}$ -MIBG will leave your child's body through the urine.
- The  $^{131}\text{I}$ -MIBG will also be in other body fluids such as saliva, feces and even sweat.



#### FOR KIDS

**MIBG is given to you through your central line. Some of the medicine then travels to the sick cells inside of your body. The rest of the medicine will come out of your body, in your sweat, poop and pee.**

- A small amount of  $^{131}\text{I}$ -MIBG will remain in your child for several days, even after leaving the hospital.

## Side Effects of Treatment

The healthcare team will treat any side effects your child may have, such as:

- Nausea and vomiting
- Discomfort from the Foley catheter
- Dry mouth
- Mild to moderate bone pain
- Lower blood counts (several weeks later)
- Low thyroid function\*

**\*MIBG can be harmful to your child's thyroid. To help protect your child's thyroid, your child will be given potassium iodide (SSKI) drops each day.**

## Handling Emergencies

It is very unlikely that your child will experience an emergency during the  $^{131}\text{I}$ -MIBG treatment. However, if your child does have an emergency, our staff is trained to provide care. There may be some limitations to the care that can be administered since your child will not be able to leave the MIBG room until the radiation drops below a certain level.

## Life at Home: What to Know after Leaving the Hospital

It can be a bit overwhelming when it is time to be discharged from the hospital. We want to make the transition as easy as we can, but there are some rules that you should know before being discharged.

### When Can We Go Home?

The stay for  $^{131}\text{I}$ -MIBG treatment is about 3-5 days. Smaller patients are often discharged sooner than larger patients since the dose received is based on body weight. Patients must stay in the hospital until the radiation level detected at one meter from the patient is less than 7 mrem/hr.

### Precautions after Leaving the Hospital

We will give you verbal and written guidelines before you go home. The purpose of these guidelines is to limit exposure to others who may be coming into contact with your child once at home, since your child will still be emitting some radiation.

- Continue to give your child potassium iodide (SSKI) or Lugol's solution until the date we told you to stop.



- Flush your toilet twice after your child uses it for the next 7 days.
- Use disposable diapers and be sure to move them to an outdoor garbage can at least once a day.
- Use disposable gloves while changing diapers for the next 7 days.
- Wash hands well with soap and water after changing diapers or handling urine, vomit or stool (even though you wore gloves).
- Bathe your child daily.
- Try to limit close contact (closer than arm's length) to no more than fifteen minutes per day for the first week after treatment. (Do not nap with your child, or hold them on your lap, if you can).
- <sup>131</sup>I-MIBG patients may not hold infants (children less than one year old) for one month after the treatment to prevent radiation exposure.
- If your child requires doctor or lab appointments after leaving the hospital, it is okay for them to go.

## Contact Information

### **Pediatric Oncology Office – (608) 263-6200**

*Call this number if you have non urgent questions for a physician*

### **Pediatric Oncology Research Office – (608) 890-8070**

*Call this number if you have non urgent questions related to research*

### **Physician on call – (608) 262-0486 and ask the operator to page the pediatric hematology/oncology fellow**

*Call this number anytime you have an urgent question or concern requiring immediate attention from a physician*

**Call 911 if you need emergency care.**

