

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

This Family Education Sheet helps you and your child to get ready for <sup>131</sup>I-MIBG treatment at Dana-Farber/Children's Hospital Cancer Care. This sheet also talks about things you and your child must do after <sup>131</sup>I-MIBG is given. This information is also shared with you in person. Please feel free to ask any questions.

### What is <sup>131</sup>I-MIBG?

Metaiodobenzylguanidine (MIBG) is a liquid absorbed by neuroblastoma cells. MIBG is mixed with radioactive iodine (<sup>131</sup>I) in the lab to form <sup>131</sup>I-MIBG. The <sup>131</sup>I-MIBG delivers radiation to the neuroblastoma cells to kill them.



<sup>131</sup>I-MIBG

### How is <sup>131</sup>I-MIBG given?

<sup>131</sup>I-MIBG is a liquid that is given to your child by a nuclear medicine technologist. The technologist works with nursing staff to give your child the correct dosage of <sup>131</sup>I-MIBG. The liquid enters your child's body through an IV inserted into your child's vein over the course of 1 to 2 hours.

Once the infusion is finished, the nuclear medicine technologist re-enters the room to flush the infusion of <sup>131</sup>I-MIBG and remove the equipment from the room.

### What happens after the <sup>131</sup>I-MIBG infusion?

After the infusion, the <sup>131</sup>I-MIBG enters your child's bloodstream and then goes to the neuroblastoma cells.

Since <sup>131</sup>I-MIBG is removed from your child's body through the urine, your child's urine has the highest levels of radiation. Because of this, your child has a urinary catheter inserted on the day of the infusion, which is used throughout most of his time in the hospital.

The urine from your child's catheter drains into a bag, which feeds into a lead-lined box

on a wheeled cart. This box is located on the side of your child's bed closest to the bathroom.

The left over <sup>131</sup>I-MIBG leaves your child's body through his urine over the next several days. The <sup>131</sup>I-MIBG is also released through other body fluids, such as spit and sweat.



Urine Collector

### Where is <sup>131</sup>I-MIBG given?

For the <sup>131</sup>I-MIBG treatment, your child is admitted to the <sup>131</sup>I-MIBG treatment room on 6 West, the Hematopoietic Stem Cell Transplant Unit at Boston Children's Hospital.

Your child has high radiation levels after the infusion, and the <sup>131</sup>I-MIBG treatment room is designed to reduce the exposure of this radiation to staff and families.

**Your child must stay in bed in the <sup>131</sup>I-MIBG treatment room during the entire hospital stay.**

### What does the <sup>131</sup>I-MIBG treatment room look like?

#### The Anteroom

The <sup>131</sup>I-MIBG treatment room is split up into two areas: a small entry room (anteroom) and the patient's room. A lead-lined door separates the anteroom and the patient room, **which must stay closed to control radiation levels.** The caregiver sleeps in the anteroom.



Anteroom Bed

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The anteroom contains **protective clothing** that you must wear when going into the treatment room to see your child. Protective clothing includes gowns, gloves, and shoe covers.

There is a specific area in the anteroom for you to put on and take off your protective clothing. A staff member shows you how to enter and exit the <sup>131</sup>I-MIBG treatment room.



Protective Clothing

### <sup>131</sup>I-MIBG treatment room

Protective measures in your child's room to control radiation exposure include:

- Lead in the walls, ceiling, floor and door;
- Two special containers for waste and linen;
- Three movable lead shields around your child's bed that are about chest high and covered in plastic wrap. **If a shield is moved, the caregiver must tell the nurse immediately;**
- Plastic-covered items and surfaces, including the floor of your child's room, bathroom and toilet area. The bathroom is where there is a high risk for contamination to happen. **You are not allowed to use your child's bathroom in the treatment room.**
- **Caregivers cannot eat or drink in the <sup>131</sup>I-MIBG room, but can eat in the anteroom.**



Lead-shielded Bed



Plastic-covered Toilet

### How can radiation exposure be minimized while caring for my child?

Below are some ways to minimize your exposure to radiation while caring for your child:

- **Limit your time in the room.** When your child is sleeping or doesn't need you in the room, spend time in the anteroom. You can also think about using different caregivers to lessen your radiation exposure.
- **Use shielding:** While in the room, stay behind the large mobile lead shields as much as you can.
- **Keep your distance:** When in the room, try to stand as far away from your child as possible.
- **Be aware of possible contamination:**
  - ❖ If you touch your child or items in the room that he has touched, you could transfer that contamination to yourself.
  - ❖ Wearing gloves and protective clothing helps to minimize contamination. We teach you how to remove and throw away these items as you leave the room.
  - ❖ **Do not remove anything from the room** without having it first checked by radiation staff.

### How can I monitor my radiation exposure while caring for my child?

To monitor your radiation exposure, you must wear a small radiation monitoring device. The radiation safety staff shows you how to use this device before your child starts the therapy.



Radiation Monitoring Device

### Who can visit my child?

Only one caregiver can spend the night with your child. **No other visitors are allowed in the room.** Women who are pregnant are not allowed in the treatment room at any time.

Visitors, including siblings, are not allowed during your child's admission.

### What am I expected to do for my child while he is in the hospital?

After your child is admitted to the hospital, the nursing staff tells you about the care that you need to give to your child while you both are in the hospital. Because nursing staff are frequently exposed to radiation, the nurses'

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contact with your child is limited to complex medical care, so that they are available if there is an emergency.

The chosen caregiver for your child must sign a contract before their child is admitted to the hospital for the therapy.

This contract says that the caregiver must:

- Help with teeth brushing and any other hygiene needs;
- Change clothing and bed linens if soiled;
- Feed their child meals;
- Give oral medicines;
- Help the child to pee in a bedpan, and empty bedpan afterwards;
- Change diapers;
- Empty the urine collection bag with nursing supervision (you are taught how to do this before admission to the hospital); and,
- Entertain your child as needed.



### What should I bring to help keep my child busy?

Try to bring toys or projects that keep your child busy for a long time.

The hospital provides as much entertainment as it can, including toys and projects that can be used and thrown away, DVDs, and PlayStation games.

**Do not bring favorite or valuable items,** such as stuffed animals, blankets or pillows to the hospital. You will not be able to take them home due to contamination.

When you come in for your meeting with the MIBG coordinator, you also meet with the Child Life Specialist to talk about items that are suitable to bring to the hospital.

### When can my child leave the hospital?

A small amount of <sup>131</sup>I-MIBG is in your child even after he leaves the hospital. The amount of radiation that can stay in your child after he leaves the hospital is determined by your child's medical condition and how much radiation can be safely exposed to others.

The radiation safety staff talks to you about the precautions you can take when you go home. The talk focuses on your child's home life and explores questions such as:

- Can your child have his own temporary private bathroom when he returns home?
- Does your child have siblings?
- When should your child return to school and after-school activities?
- When can your child travel?

Before your child leaves the hospital, he is also taught special ways to clean himself. These techniques depend on his radiation levels and are reviewed with you and your child. Instructions are also given to you in writing before you leave the hospital.

### Who can I call with study-related questions?

Please contact the MIBG research nurse to discuss any additional questions or concerns:

- **Inpatient:** Maggie Malsch, RN, BSN, CPHON at (617) 355-2068 or via e-mail at: [maggie.malsch@childrens.harvard.edu](mailto:maggie.malsch@childrens.harvard.edu)

### Who can I call for medical help?

- **Monday-Friday, 8 a.m. to 5 p.m.** - Call the Jimmy Fund Clinic at (617) 632-3270.
- **Off hours (after 5 p.m., holidays, and weekends):** Call the Page Operator (617) 632-3352 and ask for the pediatric hematology/oncology or stem cell transplant fellow on call.
- **Life-Threatening Emergencies:** Call 911.

A **Spanish** version of this is available from your provider.