131I-MIBG Treatment for High-Risk Neuroblastoma
A Guide for Family Caregivers
Introduction

This information is for family members or guardians who are providing care (referred to as family caregiver) for their children undergoing treatment for neuroblastoma with $^{131}$I-MIBG (Metaiodobenzylguanidine).

This information must be reviewed by each family caregiver participating in care. According to the Canadian Nuclear Safety Commission, SickKids’ will ensure that caregivers of patients receiving MIBG therapy are properly informed of the precautions necessary to keep exposure as low as reasonably achievable (ALARA).

This guide is a supplementation to meeting with the $^{131}$I-MIBG therapy team including radiation safety and oncology. There will be time to ask all your questions of the $^{131}$I-MIBG therapy team.
## Overview of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiation</td>
<td>A shortened term for “ionizing radiation” and is used to describe the wave or particle emitted or “given off” by a substance. ¹³¹I is the part of ¹³¹I-MIBG that emits radiation. ¹³¹I emits both gamma (wave) and beta (particle) radiation.</td>
</tr>
<tr>
<td>Gamma radiation</td>
<td>A type of ionizing radiation in the form of a wave. Gamma radiation is capable of traveling long distances through air and most other materials. Gamma radiation is useful for imaging studies that will be performed in the Nuclear Medicine Department at the end of the treatment.</td>
</tr>
<tr>
<td>Beta radiation</td>
<td>A type of ionizing radiation in the form of a particle. Beta radiation can travel only short distances. The beta radiation is what is actually providing the therapeutic part of the treatment.</td>
</tr>
<tr>
<td>Radioactive</td>
<td>A term used to describe a substance that gives off radiation. In this case ¹³¹I is the matter that is radioactive.</td>
</tr>
<tr>
<td>mRem(sievert)</td>
<td>Units of radiation measure.</td>
</tr>
</tbody>
</table>
## Overview of Terms (continued)

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pocket dosimeter:</strong></td>
<td>An instrument used to measure and calculate the absorbed dose in matter and tissue resulting from the exposure to indirect and direct ionizing radiation.</td>
</tr>
<tr>
<td><strong>Radiation meter:</strong></td>
<td>An electronic device used to detect the presence of radiation and measure radiation levels.</td>
</tr>
<tr>
<td><strong>Radiation contamination:</strong></td>
<td>The presence of a radioisotope (e.g. (^{131}\text{I})) in an undesired area. Examples are the soles of shoes or in the hallway outside the room. Contamination is essentially the presence of (^{131}\text{I}) anywhere outside the patient’s body or contained urine. Sources of contamination include urine, sweat, feces, emesis and saliva.</td>
</tr>
<tr>
<td><strong>Radiation isolation:</strong></td>
<td>A term referring to the precautions necessary to minimize radiation exposure to caregivers of patients who are radioactive from (^{131}\text{I})-MIBG therapy. Precautions include the use of personal protective equipment (PPE), lead shields and pocket dosimeters.</td>
</tr>
<tr>
<td><strong>Lead shield:</strong></td>
<td>Thick barriers made of lead, which is a very dense material and is very effective in reducing the intensity of the gamma radiation from (^{131}\text{I}).</td>
</tr>
<tr>
<td><strong>Family caregiver:</strong></td>
<td>The designated family member(s) or guardian(s) caring for the child receiving MIBG therapy.</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Radiation Safety Officer (RSO):</strong></td>
<td>The person within an organization responsible for the safe use of radiation and radioactive materials as well as regulatory compliance.</td>
</tr>
</tbody>
</table>
Section 1: What is $^{131}$I-MIBG?
What is $^{131}\text{I}$-MIBG?

- MIBG is short for Metaiodobenzylguanidine.
- It is a substance that concentrates in neuroblastoma tumours. A type of radioactive iodine ($^{131}\text{I}$) is combined with MIBG forming $^{131}\text{I}$-MIBG.
- $^{131}\text{I}$-MIBG is a clear liquid that looks like water.
- The $^{131}\text{I}$-MIBG compound is designed to deliver radiation directly to the neuroblastoma cells with the goal of killing the neuroblastoma cells.
What is $^{131}$I-MIBG? continued

- Radiation is a powerful tool against cancers. Normal healthy tissue can also be harmed by high doses of radiation.

- Because $^{131}$I-MIBG gives off radiation, the Canadian Nuclear Safety Commission strictly regulates how it can be used.

- SickKids follows Canadian Nuclear Safety Commission regulations to control the radiation from this treatment. This involves special equipment and shielding and radiation safety training for all staff who care for patients receiving $^{131}$I-MIBG therapy at SickKids.
**131I-MIBG Therapy**

- **131I-MIBG therapy** is only available at hospitals approved to use 131I-MIBG. Patients must be admitted to SickKids to receive this therapy.

- The average hospital stay is 3 to 5 days, but may be longer for patients that live far distances from Toronto.

- Two family caregivers will be required with one family caregiver available at all times to help with daily care.

- Your child’s 131I-MIBG therapy team will explain the process of 131I-MIBG therapy and what the family caregiver(s) role in therapy is. This information is also included in this guide.
Why does my child need to stay in the hospital?

• Your child will receive $^{131}$I-MIBG therapy through a Central Venous Line (CVL) or Port-O-Cath. It enters the bloodstream and a portion will go to the neuroblastoma cells.

• Most of the remaining $^{131}$I-MIBG will be eliminated through the urine over the next several days. This urine is radioactive.

• Other bodily wastes are radioactive as well including saliva, sweat, stool and blood.

• As a result, people around the patient may be vulnerable to radiation exposure.

• SickKids has the training and equipment to ensure that radiation exposure remains as low as reasonably achievable (ALARA).
Why does my child need to stay in the hospital?

• Federal law requires that patients who get high doses of radiation such as $^{131}$I-MIBG therapy be admitted to hospital and remain in radiation isolation. The Canadian Nuclear Safety Commission (CNSC) regulates safety precautions to be followed in the patient room including design of the room (lead lined walls, floors and shielding).

• Your child will be discharged from the hospital when radiation levels are at a safe value to follow precautions at home. The Radiation Safety Officer (RSO) will monitor radiation levels closely.

• Once your child is ready to go home, The RSO will provide you with guidelines to follow at home as your child will still be emitting radiation.
Section 2: What is involved in $^{131}$I-MIBG therapy?
What are the steps needed before the start of therapy?

- Your child will need to have a variety of tests and procedures in the weeks before the MIBG therapy date. (examples: CT, MIBG, echo, GFR, bloodwork) Some of these tests can be done at your home hospital.

- During the week before the therapy, it is important that your child avoids medicines that make $^{131}$I-MIBG less effective. This includes common cold medicines. The $^{131}$I-MIBG team will review this with you.

- The night before the treatment, your child will start receiving two thyroid-protecting agents to protect his/her thyroid gland from being harmed by radiation.

- Your child will need a Foley (urinary) catheter to drain the bladder because his/her urine will be radioactive. This will be inserted under sedation the morning of the $^{131}$I-MIBG therapy infusion.

- It may be necessary to insert a Peripheral IV as well.
Where does the $^{131}\text{I}$-MIBG come from?

- $^{131}\text{I}$-MIBG for this therapy is made by a pharmaceutical company.

- The company ships the frozen $^{131}\text{I}$-MIBG to SickKids within the 24 hours before treatment.
How is the $^{131}$I-MIBG administered?

- After the frozen $^{131}$I-MIBG is thawed, it is placed in a large syringe by a Nuclear Medicine Technologist.

- The radiopharmacy where the $^{131}$I-MIBG will be prepared is attached to the MIBG suite.
How is the $^{131}$I-MIBG administered? (continued)

- The syringe of $^{131}$I-MIBG is connected to a lead lined infusion pump and brought into the patient room on a cart surrounded by lead bricks.
How is the $^{131}$I-MIBG administered? (continued)

- The $^{131}$I-MIBG will be administered from the syringe into your child’s central line. The infusion pump slowly pushes the plunger of the syringe administering the drug.

- It will take 90 to 120 minutes for the $^{131}$I-MIBG infusion to complete.

- Family caregivers and health care providers must limit their time in the room during the infusion.
Who will give my child the $^{131}$I-MIBG?

- The nursing staff will get your child ready for the infusion.

- The nuclear medicine technologist will give the $^{131}$I-MIBG using the infusion pump. The technologist will be in the ante-room during the infusion.

- A Nuclear Medicine Physician and a Oncology Physician will be available but not in the room during the infusion.
What will happen to the $^{131}$I-MIBG after it is administered?

- After administration, the $^{131}$I-MIBG will find its way through the bloodstream to the neuroblastoma cells.

- Most of the remaining $^{131}$I-MIBG will be eliminated through the urine over the next several days while your child is in the hospital. The $^{131}$I-MIBG will also be in other body fluids such as saliva, stool and sweat.

- Your child will be in radiation isolation as soon as the $^{131}$I-MIBG infusion is started.

- The therapy effects of $^{131}$I-MIBG will continue for several weeks after the $^{131}$I-MIBG has been given.
Therapy Side Effects

The 8A medical team will manage possible side effects from $^{131}$I-MIBG these may include:

- Nausea and vomiting: this may happen in the first 24 to 48 hours after the infusion.
- High blood pressure (hypertension)
- Short-term loss of appetite
- Jaw pain and/or dry mouth
- Discomfort from the urinary Foley catheter
- Low blood counts, this will occur in the weeks following $^{131}$I-MIBG therapy and will be managed as an outpatient at your home center.
Therapy Late Effects

• Hypothyroidism - 5-20% of patients
• Secondary malignancies such as:
  Myelodysplastic syndrome (MDS)
  AML
Secondary malignancies - approximately 3-5% of patients
Section 3: Getting ready for therapy
How does this therapy affect family caregivers?

• All caregivers, including family caregivers, must follow strict radiation protection guidelines during this treatment to limit their exposure to radiation.

• Many safeguards will be in place, like wearing protective clothing, utilizing lead shields and wearing dosimeters to measure radiation exposure.

• You must limit direct physical contact with your child during this treatment. You will be guided daily by the RSO as to the time that can be spent in close proximity to your child.
I-MIBG Suite layout:

The anteroom is outside the radiation zone, where caregivers will prepare to enter and exit the patient and family caregiver space. The patient can also be monitored from this room.
131I-MIBG Suite layout:

Patient area: view from the family caregiver area

Family caregiver area

SickKids

This is the patient bathroom, there is a toilet and a shower. The RSO will tell you when your child is allowed to use the shower and the toilet.

Before they can use the toilet a foley catheter and portable commode will be used.

Bed baths will also be done until the RSO clears the patient for showers.

The bathroom is for patient use only.
What can I expect about my child’s room?

- Your child will stay in a special room with lead-lined walls and floors to minimize radiation exposure to others.

- Portable lead shields surround the bed and separate the patient area from the family caregiver area. When in the room, family caregivers should stay behind the second set of lead shields whenever possible.
What can I expect about my child’s room?

- A lead box near the bed will hold and shield your child’s urine collection bag (Foley bag).
- A urine pump will take the urine from the urine bag to the continuous drainage system to a pipe leading to the sewer.
Room Preparation

- Surfaces of the room that may be touched (floor, bedrails, etc.) will be covered with plastic.

- Equipment and items that could be touched by your child such as the telephone and remote control will also be covered with plastic.
Room Preparation

- There are separate containers for linens, waste and PPE.

- There will be a lead lined linen disposal and a lead lined waste disposal for waste such as diapers.

- These containers will be pointed out to you during orientation to the suite.
Room Preparation: Radiation Monitoring

- There is a radiation monitor mounted on the ceiling in your child’s room.

- This monitor will continuously tell us how much radiation your child is giving off.

- A Radiation Safety Officer will check levels daily.
Family caregiver responsibilities

• The patient caregiver will be asked to participate in many aspects of the patient's care as outlined in the $^{131}$I-Metaiodobenzylguanidine (MIBG) Therapy Family Caregiver Guideline.

• Examples of this are:
  • Assist child with bathing and hygiene needs (i.e., brushing teeth)
  • Give all oral medications to your child
  • If nauseous, provide your child with emesis basin
  • Help your child with bathroom needs

• A copy of the $^{131}$I-Metaiodobenzylguanidine (MIBG) Therapy Family Caregiver Guideline will be given to you.
Section 4: Making the best of your time in hospital
What can we bring to the hospital?

- You can bring your luggage and belongings into the ante room, a room connected to but separate from the patient room.

- Personal items are not to be brought into the patient area without approval from the RSO.

- Items brought into the patient area may become contaminated after $^{131}$I-MIBG has been administered and may have to stay at SickKids for up to 3 months.

- All personal items will be screened by the RSO prior to discharge.
What about items that are special to my child?

- You should plan to leave anything at home that you do not want thrown away.

- Any item that your child handles, including clothing worn, will most likely become contaminated with $^{131}$I, these will be treated as radioactive and cannot be returned to you.

- It is recommended that you bring disposable toys and comfort items for your child to play with during the treatment.

- SickKids Child Life will also provide activities and small toys for your child during their admission.
What can my child do during treatment?

• Your child will have to remain in bed most of the time during treatment with the exception of using the commode or toilet.

• Your child may play video games, watch TV or movies, play with toys etc. however, you will need to put the movies/games in the players for your child.

• Family caregivers should make sure that your child avoids touching things outside of the bed area.
What may I do during the treatment?

• As a family caregiver, you are expected to actively participate in your child’s care throughout his/her treatment.

• You will care for your child by assisting them with taking medications, going to the bathroom, eating and other necessary activities.

• When you are in the patient area, you must remain behind the lead shields surrounding the bed.

• There is a family caregiver area located within the patient room behind the second set of lead shields that the family caregiver can stay and sleep in. Only one caregiver will be allowed in the suite at a time
Section 5: Family caregiver instructions and safety procedures
What general restrictions will I have to follow during treatment?

- You will be allowed in the family caregiver area in the suite during the therapy, staying behind the second set of lead shielding whenever possible. The following will apply to you while in the room:
  - No eating or drinking
  - Wear appropriate personal protective equipment (discussed below)
  - Follow all radiation safety precautions (discussed below)
  - Wear a dosimeter (discussed below)
  - Do not use the bathroom in the room
  - Only one patient caregiver is allowed in the room at a time (except for brief periods of time for transition)
Will I be exposed to radiation?

• Yes, you will be exposed to radiation during the treatment.

• Your radiation exposure will be kept as low as reasonably achievable (ALARA) by following the guidelines and the instructions that your child’s care team gives you. How well you follow the recommended precautions will greatly affect the radiation dose you receive.

• By following the precautions outlined, you will not only minimize your radiation dose, but also the radiation dose to others (e.g. by not spreading contamination).
What ways can I be exposed to radiation?

- Exposure to radiation can be divided into the following two basic categories:
  - External radiation exposure
  - Internal radiation exposure
External Radiation Exposure

• You will be exposed to gamma radiation being emitted from the $^{131}$I that is in your child. The gamma radiation is emitted from your child in all directions – similar to a light bulb giving off light. The closer you are to your child, the higher level of gamma radiation you will receive.

• Another source of gamma radiation exposure is the urine. This is why it is stored in a lead box during collection.
Internal Radiation Exposure

• This type of exposure mainly results from $^{131}$I hand contamination. Any contamination on the hands can be transferred to food items which, in turn, can transfer the contamination ($^{131}$I) inside your body. Once the $^{131}$I is in your body, exposure from the beta and gamma radiation occurs.

• Because of the precautions taken during therapy, this type of exposure is highly unlikely.
How much radiation will I receive?

- Patient caregivers usually receive between 50 mRem (0.5 mSv) and 300 mRem (3 mSv) during their child’s $^{131}$I-MIBG treatment. The Canadian Nuclear Safety Commission limits a family caregiver to 400 mRem (4 mSv) per year. The limit for medical staff is 100 mRem (1 mSv) per year.

- By comparison, a person living in the Canada receives a “natural” background radiation dose of about 213 mRem (2.13 mSv) per year.

- The table on the next page compares radiation doses received during common tasks of daily living to those received during medical imaging and treatment procedures.
What are the risks to Radiation Exposure?

Table 3: Radiation doses, dose limits and potential health effects

<table>
<thead>
<tr>
<th>Dose</th>
<th>Limit or Health Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 5,000 mSv</td>
<td>Dose that may lead to death when received all at once</td>
</tr>
<tr>
<td>1,000 mSv</td>
<td>Dose that may cause symptoms of radiation sickness (symptoms include tiredness and nausea) if received within 24 hours</td>
</tr>
<tr>
<td>100 mSv</td>
<td>Lowest acute dose known to cause cancer</td>
</tr>
<tr>
<td>30–100 mSv</td>
<td>Radiation dose from a full-body computed axial tomography (CAT) scan</td>
</tr>
<tr>
<td>50 mSv</td>
<td>Annual radiation dose limit for nuclear energy workers</td>
</tr>
<tr>
<td>1.8 mSv</td>
<td>Average annual Canadian natural background dose</td>
</tr>
<tr>
<td>1 mSv</td>
<td>Annual public radiation dose limit in Canada</td>
</tr>
<tr>
<td>0.1–0.12 mSv</td>
<td>Dose from lung X-ray</td>
</tr>
<tr>
<td>0.01 mSv</td>
<td>Dose from dental X-ray</td>
</tr>
<tr>
<td>0.01 mSv</td>
<td>Average annual dose due to air travel</td>
</tr>
</tbody>
</table>
Health Effects of Ionizing Radiation

There are two possible outcomes from chronic low-level exposures of ionizing radiation:

- **Cancer**: A radiation dose above 100 mSv is known to increase the likelihood of cancer, depending on the amount and type of radiation, the person's sensitivity to radiation, and other factors, such as the dose rate. Doses below 100 mSv are also believed to increase the likelihood of cancer. However, the incidence of cancer associated with doses below this level has not been distinguished from that of the general population. The risk from radiation exposure is considered proportional to dose and so small doses of radiation would have a proportionately small risk. Therefore, if there is a small dose of radiation, it is very unlikely that any health effect would occur.

- **Hereditary effects**: The effects of radiation have not been observed in the children of parents who were previously exposed to radiation. However, these effects have been seen in experimental animals and in plants, so to be prudent dose limits do account for them.

Studies in humans show no conclusive evidence that chronic radiation doses much lower than 100 mSv can lead to cancer. However, scientists assume that lower radiation doses pose a lower likelihood of health effects, and that these effects are proportionally less likely as doses approach zero. This is a key concept in radiation protection and the foundation of the ALARA principle, which states that radiation exposure should be kept **As Low As Reasonably Achievable**.

To protect members of the public and workers from the effects of radiation as a result of the nuclear industry, the CNSC has set the following dose limits:

- **1 mSv/year** for members of the public (for artificial sources over and above natural background and medical radiation). An exposure of 1 mSv would give a lifetime risk of 5.5 in 100,000 of fatal and non-fatal cancer. This risk of cancer is no different from that of the general population.

- **50 mSv/year** for nuclear energy workers (or 100 mSv during a five-year dosimetry period).
How can I prevent or reduce my exposure to external radiation?

• **Minimize the time** you spend near your child

• **Maximize the distance** between you and your child as much as possible (the radiation level falls off rapidly with distance)

• **Stay in the family caregiver area** as much as possible

• **Stay behind the mobile lead shields** as much as possible
How can I prevent or reduce my exposure to internal radiation?

- Wear personal protective equipment (PPE) when touching your child or anything that your child has touched.

- You will be taught how to enter and exit the patient care area following radiation safety principles.

- Do not eat or drink while in the room.

- Wash your hands after leaving the room.
What precautions will I have to take when entering the room?

- All patient caregivers must put on personal protective equipment (PPE) before going into the patient area:
  - Disposable shoe covers
  - Two pairs of disposable gloves
  - Disposable gown
  - Eye shield, if needed
  - Hairnet, if needed
  - An electronic dosimeter
How will I monitor my radiation levels?

- Family caregivers are given their own electronic radiation monitoring device, called a “dosimeter”.

- Make sure you wear the dosimeter underneath your gown, clipped onto your clothing at waist level.

- You must wear it at all times while in your child’s room.

- This device measures the family caregiver’s radiation exposure during your child’s stay in the hospital.
How do I use the instant read dosimeter?

- SickKids staff will teach family caregivers how to use the dosimeter.
- Instructions for dosimeter use will be posted in the ante room.
- All readings must be recorded in the dosimeter log.
What will I have to do when leaving the patient area?

- When leaving the patient area, first remove the first pair of gloves.
- Next, take off the shoe covers one at a time. As each shoe cover is removed, place your uncovered foot just outside of the patient area.
- Remove your gown rolling it from the inside out.
- Finally, remove the second set of gloves.
- All removed protective clothing should be placed in the waste container located at the exit of the patient area.
What will I have to do when leaving the patient area?

- After taking off all of your protective gear, check yourself for contamination.

- A radiation survey meter located in the ante room is used to check your hands, body and feet for radioactive contamination. The RSO will show you how to do this.

- The meter tells you whether you have any radioactive material on you.

- The most likely area of contamination will be on the palms of your hands.
Using and reading the survey meter

• Look at the needle on the survey meter. If it moves all the way to the right, there is contamination.

• If you discover contamination, immediately wash your hands and then check them again. Repeat hand washing and checking the monitor until the needle position is no longer at the right when checking your hands.

• Notify nursing staff.

• If no contamination is on your hands, continue monitoring the rest of your body.
Using the survey meter

- Put your hand about ¼ inch from the radiation detector. Slowly move each hand over the entire surface of the detector.
Surveying your body

Along with education by the RSO, there are posters hanging on the wall by the survey meters to illustrate how to use them. Nursing can also review use of the meters with you.
Recording your dosimeter reading

- After you have finished checking yourself for contamination, you will remove your dosimeter and record the number in your log book.
- The RSO will review all dosimeter readings daily and will speak with you about any reading outside of the expected measurement and if any actions need to be taken.
Section 6: Additional considerations
How is radioactive waste handled?

- All the waste collected in the waste containers during the treatment is most likely contaminated and therefore must be treated as radioactive waste.

- This waste is collected daily and taken to a specialized waste storage facility and held or approximately 3 months. At this time $^{131}\text{I}$ will be gone and the waste can then be disposed of as normal medical waste.
What about pregnancy?

- If you are pregnant, you will not be allowed in the room at all during the treatment.

- If there is a pregnant individual living in the house the RSO will discuss this in the discharge instructions. It may be necessary to have the patient stay longer in hospital.
What about other visitors?

• No other visitors are allowed besides the designated family caregivers.
How will emergencies be handled?

- Your child will receive the same level of care as any patient would receive in an emergency situation.

- If your child needs to receive intensive care support, the Intensive Care Unit (ICU) staff will discuss with the MIBG care team including the RSO if ICU care will be provided in the MIBG suite or in the ICU. This will be dependant on the radiation levels that your child is emitting.
Section 7: After treatment
When can my child go home?

- It is required that patients treated with $^{131}$I-MIBG therapy stay in the hospital until their radiation level is below a specific level. The Radiation Safety Officer (RSO) will check this level daily.

- Usually, the hospital stay is 3 to 5 days but could be longer.

- When your child leaves the hospital, he/she will still have a measurable radiation level however, the RSO will provide you with detailed discharge instructions on radiation safety in the home.
Guidelines and Precautions for Home Care

- Continue thyroid-protecting agent (lugols solution) as instructed for 6 weeks after $^{131}$I-MIBG therapy.

- The Radiation Safety Officer will give you detailed instructions that must be strictly followed after your child is discharged from SickKids. Your instructions will be tailored to your home set up, these instructions may be different from other families instructions.
**DISCHARGE INSTRUCTIONS FOR PATIENTS RECEIVING**

**131I-MIBG THERAPY**

Your child was administered _____ millicuries of 131I-MIBG on __________. Most of the radioactivity in your child was eliminated during the hospital stay in radiation isolation, but small amounts will continue to be eliminated in the urine and feces. Other members of your family and the public will be exposed to a small amount of radiation if they are close to your child for long periods of time, so it makes sense to take some steps to reduce this exposure as much as possible.

If your child is in need of any medical care, the medical personnel should be informed about these instructions.

There are 3 basic principles to follow for radiation safety:

1. **Distance** – the greater the distance from others, the less radiation they will receive. Try not to remain in close contact with other people for longer than necessary. Even a distance of a few feet will greatly reduce exposure.
2. **Time** – radiation exposure to others depends on how long you remain close to them. Try to minimize the time you spend in close contact with others.
3. **Hygiene** – good hygiene reduces the possibility that other people will be contaminated with the radioactivity as it leaves the body. Since most of the 131I-MIBG leaves the body in the urine, good toilet hygiene and careful washing of hands is very important to reduce the possibility of contamination. If your child uses diapers, disposal of diapers and careful hand washing after the diaper change is very important.

To help use the basic principles, these guidelines should be followed until:

(date)____________________

1. Travel home with only one adult if possible, no siblings please. Try to keep a maximum distance between you and your child in the car.
2. Minimize the time your child is in close contact with other people at home (no closer than 3 feet or 1 metre for no more than 1 hour per day)
3. Your child will avoid pregnant women and young children.
4. Your child will not go to school or daycare.
5. Have a bathroom for private use and use good hygiene habits: bathe/shower daily and wash hands frequently, especially after urinating. Flush the toilet twice after each use with the toilet lid closed (males should sit for urinating to avoid splashing). On the 7th day, the toilet, sink, bathtub/shower and floor can be thoroughly cleaned with your regular cleaning product.

6. If your child uses diapers, place the dirty diaper into a plastic bag, seal tightly and throw into a garbage container that is stored in an area away from people, such as a garage or a shed. Thorough hand washing after the diaper change is very important.
7. Your child should drink plenty of fluids during this time and be encouraged to urinate frequently.
8. Your child will use separate eating utensils and not share personal items such as towels, washcloths, combs, toothbrushes, etc.
9. After the 7th day, launder all of the bath towels, bed linens, and clothing separate from other family members’ laundry using your regular laundry products.
10. Do not share a bed or bedroom with other siblings.

If you have any questions concerning these instructions please contact Nuclear Medicine at (416) 813-6065 on week days from 8:00 am – 4:30 pm or after hours page the on call radiation safety officer at (416) 235-8954.

To call the pager: call (416) 235-8954 and you will hear a message “please enter your number on a touch tone phone after the tone”. When you hear beeps, enter in your phone number including the area code and push the pound key (#). You will then hear “message sent” and you can now hang up.

**Acknowledgement:**

I have been instructed to follow the precautions listed above to minimize radiation exposures to others and I agree to comply with these instructions.

__________________________ __________________________
Patient Signature Date

__________________________ __________________________
Parent or Guardian Signature Date

__________________________ __________________________
RSO or Treating Physician Date
Section 8: Questions and contacts
What if I have questions about the therapy?

• We realize this information may seem overwhelming.

• While reviewing this booklet, we encourage you to write down any questions that you have about this treatment experience.

• The MIBG care team are happy to answer any questions that you have at any time.
What follow up happens after discharge?

- Follow up can happen at your home institution.
- When you return home your child will require a CBC/diff to be done twice weekly with your primary team.
- Your child will most likely require transfusions of platelets and red blood cells for a few weeks following MIBG therapy.
- Your child will require GCSF (Filgrastim) to be given when/if the neutrophil count drops below 0.75
- Depending on count recovery it may be necessary for your child to have their stem cells reinfused.
- Your child will have a MIBG scan done 7-9 weeks post treatment
# Contacts

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Email</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karen Fung</td>
<td>MIBG Therapy Patient Navigator</td>
<td><a href="mailto:mibg.info@sickkids.ca">mibg.info@sickkids.ca</a></td>
<td>416-813-6801</td>
</tr>
<tr>
<td>Denise Mills</td>
<td>Neuroblastoma/MIBG Nurse Practitioner</td>
<td><a href="mailto:denise.mills@sickkids.ca">denise.mills@sickkids.ca</a></td>
<td>416-813-7654 ext 202629</td>
</tr>
<tr>
<td>Susan McQuattie</td>
<td>Radiation Safety Officer</td>
<td><a href="mailto:susan.mcquattie@sickkids.ca">susan.mcquattie@sickkids.ca</a></td>
<td>416-813-7510</td>
</tr>
</tbody>
</table>
Certificate of Completion

This is to certify that

Name ______________________________________

has reviewed the $^{131}$I-MIBG Family Caregiver Guide.

Signature ______________________________________

Date ______________________________________