

Comer Children's Hospital

Parent Tips for MIBG Therapy

Prior to MIBG therapy

About two weeks prior to MIBG therapy you and your child will come to the hospital for a consultation and evaluation. During that time you will meet with Dr. Cohn, the research nurse, radiation safety staff, child life and social work. At the end of the appointment you will be given a tour of the inpatient floor and the MIBG room, if it is not in use.

Alyssa Kirk, the research nurse, and one of our child life specialists will call you before you come for this appointment to get some initial information about you and your child. Alyssa will ask about your child's prior and current treatment. The child life specialist will discuss your child's interests, items you can bring and things they can provide to personalize the MIBG room during your time in it.

The evening before the infusion you will be admitted from home to the 6th floor of Comer Children's Hospital to the MIBG room. The next morning your child will go to the pediatric sedation area to have a urinary catheter placed and possibly a nasal feeding tube if he/she is unable to take medications by mouth. You will be given instructions to make sure your child has nothing to eat/drink starting at midnight.

Plan to get the room all set up for treatment the night before, because after the MIBG infusion, your time with your child in the room will be very limited for several days. One suggestion is to tape plastic bags to the sides of the bed with activities and snacks to help keep your child entertained and self-sufficient if he/she is old enough to work independently. Child Life will be helping to get bedside activities that he/she will like.

There is a small refrigerator in the room where you can store your child's favorite drinks and snacks, which can make taking medicine a little easier. Don't take anything into the room that you and your child can't live without. If items become contaminated with radioactivity, they will need to be stored at the University of Chicago by the Radiation Safety Office for at least three months before they can be returned to you. It is best to bring substitute special things that can be thrown away or left behind without distress to you and your child.

The night before the MIBG infusion, your child will need to take what is called a "loading dose" of potassium iodine (SSKI). It is given throughout the hospital stay to prevent his/her thyroid gland from taking up the radioactivity from the MIBG. These doses before the infusion are rather large so you should have a plan in place to help your child best take these medicines. Suggestions such as taking the

medicines with a little bit of a favorite soda or directly from the syringe with a treat to follow may make it easier.

Your child will also start getting large amounts of IV fluids through his/her central line to make sure the bladder catheter is working well and not leaking. The fluids will run at a high volume for several days after the MIBG infusion to protect the bladder and help get rid of the radioactivity in the urine.

If your child is not diapered, we can give you a bedpan to practice it with them before the infusion. You will be in charge of that activity until your child is allowed to use the toilet for bowel movements. Your child will not be able to get out of bed to use the toilet until after the bladder catheter is removed, which is typically 2-3 days after the MIBG infusion. If your child is not toilet trained at night, the catheter will have to stay in until he/she is discharged from the hospital. If needed, your child can be given laxatives and stool softeners to be sure there is a bowel movement everyday after the infusion because some of the radioactivity is eliminated in the stool. You will do all the diaper duty if your child uses diapers. You will be shown how to empty, wrap and dispose of diapers properly.

The Day of the MIBG Infusion

The morning of the MIBG infusion, the bladder catheter will be hooked up to a pump and the urine will be flushed directly into the toilet. Your child will be hooked up to a blood pressure cuff, a pulse-oximeter, and a heart monitor during the MIBG infusion. It typically takes 90-120 minutes. The infusion itself is pretty uneventful, with different staff members watching the IV site, the infusion, the monitors, and checking that all is going well. If your child feels anxious, he/she can be given medicine to calm him/her. With the catheter hooked up to the toilet and your child restricted to the bed, it is best for him/her to wear a hospital gown or p.j.'s in case there are spills or accidents with food, urine or bowel movements. The lead shields around the bed provide for plenty of privacy.

Time in the room is limited each day, typically with only 15 minutes per adult on the first day. The time increases each day. You should do as much as possible for your child from outside of the lead shields. Before entering the room, you must put on a gown, booties and gloves and a dosimeter (that detects levels of radiation exposure) to protect yourself from radioactivity contamination. You will be instructed on how to put on and take off the protective clothing and be shown how to log your name and dosimeter readings before entering and after leaving the room. You also will need to check your hands and feet with the Geiger counter when leaving the room after removing all the protective clothing.

The afternoon following the MIBG infusion, your child will receive the potassium iodine medication every 4 hours, including overnight.

The Days After the MIBG Infusion

Now comes the biggest challenge of keeping your child entertained. Each day his/her level of radioactivity decreases and your time with him/her in the room increases. Be sure you save some time each day for overnight because the nighttime medications can often be a real challenge.

Have a stock of movies, books and bedside activities that your child likes and can do alone. The Child Life department has a selection of all these activities. Be sure to check with them regularly for new things.

After several days, the bladder catheter can be removed if your child is toilet trained. This is a good time to use hospital pants. Families tend to lose their own pants due to radioactive urine dripping on them.

Your child will have an MIBG scan done before leaving the hospital. These scans are to see how well the MIBG was taken up by his/her tumor(s). Your child will not need another MIBG injection or any additional potassium iodine for this scan.

Information for Parents

You will not be able to sleep or shower in the room with your child. There is a room next to the MIBG room is used for parents to take breaks and showers. There is also a recliner chair in the anteroom, which is attached to the MIBG room, where you can sit, watch and communicate with your child. Whenever possible, we recommend that two caregivers are present during treatment to allow each person to take longer breaks and lessen the radiation exposure. If you need to keep any food/drinks for you in the hospital, you can do so in the fridge in the parent room. You will not be allowed to eat or drink anything inside your child's room.

Going Home

When your child is ready to be discharge from the hospital, you will be given special radiation safety instructions to follow and a written discharge plan that outlines when to do blood tests, see your doctor, get follow-up scans and other tests and when you plan to return to the clinic for follow-up. You will be sent home with enough of the potassium iodine medicine for you to continue for 6 weeks.

Everything in your child's room will be checked for radioactivity before you can pack it up for home. If anything is contaminated, you will be given the option of throwing it away or having it stored for you by the Radiation Safety Office until it is no longer radioactive.