

Coping with MIBG Therapy

MIBG therapy is a treatment for refractory or relapsed neuroblastoma using “radio-labeled” MIBG molecules. A radioactive isotope of iodine is connected to the MIBG molecule which is selectively taken up by NB cells. This therapy is very similar to the MIBG scans used to detect NB, but a much higher dose is used. The scans usually use iodine-123 (faster decay) whereas MIBG treatment uses the slower decaying iodine-131 isotope.

Some trials combine high-dose chemotherapy¹ with the MIBG therapy, and the side-effects and coping discussion that follows will not apply to the extra effects of the chemotherapy. In July 2008 a trial opened using a new MIBG “formulation” which is 20 times more concentrated with radio-labeled MIBG molecules and is known as MIP, Azedra, or Ultratrace.² Ultratrace has similar side-effects, but as of this writing few patients have been treated so we have little information about the differences, if any, between the two MIBG formulations.

MIBG therapy (without chemotherapy combination) is in some ways an easy treatment; unlike some other treatments, it is usually not painful and doesn’t tend to make most children feel sick. Still, it is a major treatment that can bring significant upheaval with it. This section provides information on the special requirements of MIBG therapy and a few suggestions for coping from families who have experienced it.

Traveling for the Treatment

One of the first hurdles for most families will be the need to travel to a distant city for an extended stay, since at present, MIBG therapy is available only in a few places around the country. Arrangements for housing can usually be made through the Ronald McDonald House or other similar program for families. For example, families traveling to San Francisco for treatment at the UCSF Children’s Hospital utilize an organization called Family House. Usually the doctor’s office at the hospital will put you in touch with the appropriate agency. If not, call the social workers at the hospital where your child will be treated. See “Finding Support Resources.”

Receiving MIBG Treatment

MIBG therapy is administered as an IV infusion that lasts about 90 minutes. Children receiving MIBG therapy are checked into a lead-lined hospital room. Their hospital bed is surrounded by two or three large lead shields, which protect parents and others from exposure to the radioactivity. Because children who receive the treatment are themselves radioactive, they must remain in the hospital room from two to five days and are confined to the bed except for necessary trips to the toilet or to another part of the hospital for a scan or medical procedure. The level of radiation being emitted from a child’s body is constantly measured, and discharge is only permitted when the amount of radiation emitted drops to a certain level. The typical length of stay is 2 to 5 days, with smaller children generally having shorter stay times than larger children, since the dose administered is based on body weight.

The Children’s Hospital of Philadelphia, one of the locations where MIBG therapy is available, has provided online, illustrated guides for parents at <http://stokes.chop.edu/programs/maris/MIBG.pdf> and for children at <http://stokes.chop.edu/programs/maris/mibg4.pdf> that describe the therapy experience.

Limited Physical Contact with your Child

One concern parents always have about MIBG therapy is the limited physical contact with their child. For the first one to three days after the infusion, physical contact with the child must be very limited due to high levels of radioactivity. Only one parent or caretaker may stay with the child, and generally that person must remain on the far side of the room until the child's radiation level drops, although parents can assist with taking medications, going to the bathroom, eating, and other necessary activities. Children and pregnant women are NOT allowed in the room.

In some hospitals, it may be difficult to actually see the child, depending on how the lead barriers are placed. Often a large mirror is placed on one side of the bed so that parent and child can see each other. Some children find it difficult to have so little physical contact with their parents for several days, and very young children may need some light sedation. You may wish to start telling your child several days in advance that they will have to stay in bed, and that you will have to stay on the other side of the room.

Most of your time will be spent in a designated chair, which will probably be a sleep chair. It may be helpful to ask additional family members or friends to come in. Each individual can be in the room for a prescribed amount of time (a maximum of an hour at some hospitals) to help entertain and reassure the child.

Coping with the Safety Precautions

Federal regulations require many safety precautions for patients receiving radiation therapy. You will be given detailed information on the various safety precautions required. Although the precautions for MIBG therapy vary from hospital to hospital, there are similarities. Every surface in the room, including the floor, will be covered with plastic, as well as any object the child touches, such as the telephone or video game controller. Parents are required to wear disposable gloves and a paper gown when caring for the child, and persons entering the room must wear paper shoe coverings that are disposed of upon leaving the room. Some hospitals may not allow parents to eat or drink, or use the bathroom, in the room.

Parents and visitors must wear a small badge or meter to measure the radiation exposure. The amount of radiation received by a parent staying with the child the entire time is at a safe level and will be explained to you. In order to limit the amount of time they spend in the room and the amount of radiation exposure they receive, nurses may rely on you to give any medications. This is necessary for their safety—parents may experience the radiation exposure that comes with MIBG therapy once or twice in a lifetime, but nurses are exposed to it frequently on the job, and need to limit exposure to avoid endangering their own health.

There will be several large cardboard boxes lined with red bags in the room, and all waste and linens must be disposed of in these boxes. Anything that you do not want to end up in the trash should be left at home. Toys and favorite blankies, stuffed animals, or other objects are usually allowed into the room, but if they become too "hot" (radioactive) they may not be allowed back out. Plan to bring disposable toys, coloring books, etc. for your child to play with during the treatment, because any item that your child handles, including toys and clothing worn, will generally be disposed of.

Several parents have reported that their child became attached to a particular toy and was upset when required to part with it at the end of the treatment. Some parents recommend buying a duplicate of a favorite toy to avoid this problem. Another parent coped with the problem by bringing a favorite doll wrapped in plastic so that it could be brought back home.

Some hospitals will allow items to remain in a locked storage to decontaminate and be recovered by you after about 3 months. However, you do not want to risk losing a favorite blanket or stuffed animal! Talk with the people at the specific hospital to find out their procedures in advance, so that you can begin forming a strategy for replacing, duplicating, or otherwise bribing your child to do without, his or her favorite comfort object.

You can bring your luggage and belongings into the room. However, these items will need to be stored away from the bed such as behind the chair that you will be sitting and sleeping on.

Each hospital has slightly different rules and practices, but most seem willing to do what is reasonable to help your child through the process.

Coping with Boredom

Boredom tends to be the big issue with MIBG treatments because of the period of time the child is required to be alone as well as the fact that the child tends to feel quite well during the treatment. There will be video games such as Nintendo in the room and a VCR or DVD machine for the TV. If the video or game machine is beyond the lead barrier around the bed, videos and games from home may be used and brought home when you leave. Your child may be given a game controller or TV remote control wrapped in plastic, or otherwise will be required to wear plastic gloves while using them. Child life specialists can bring disposable craft materials, movies, and video games. Other inexpensive board games can be used in the room and later trashed if necessary. The age of the child will determine what activities are best for keeping them occupied and distracted, but packing a “bag of tricks” is certainly important. When all else fails, go to the cafeteria and bring back a big bowl of ice cream!

You may get pretty lonely yourself, so bring some good novels or other diversions. One parent stated that a prepaid calling card was a sanity saver, as some hospitals may restrict the use of cell phones, or the signal may be very poor.

Physical Complaints during Treatment

Virtually every parent of a child that has received MIBG treatment found the most difficult issue for the child was having a Foley catheter in place for an extended period. The catheter is considered necessary because patients are given much hydration to protect the bladder and the catheter continually empties it, protecting the child from unnecessary exposure to radiation. Catheters are generally inserted under general anesthesia and remain in place for a couple of days. Some children find the catheter does not hurt at all. Others will feel some mild discomfort or be bothered by it, as it does restrict movement somewhat, while still other children complain that it does hurt. One parent recommends using lidocaine ointment topically as needed. When the child’s radiation level is low enough the catheter will be removed. Older children may not be required to have a Foley catheter system but will need to be awakened every 2 hours to urinate.

Although the radiation dose is high, the only physical side effects generally reported during administration of the MIBG treatment are mild nausea and vomiting. Some parents have said their child just didn’t feel well and refused to eat much during the treatment. MIBG affects the salivary glands and children may look swollen for a few days or have cheek pain requiring pain medication. One parent reported her child had diarrhea for about a week after finishing the treatment.

Restrictions after the Treatment

After leaving the hospital, the federal regulations do not apply. However, your child will still be radioactive, and you will be given recommendations intended to minimize radiation exposure to others. You will need to avoid too much lap time, especially if you are expecting or may be pregnant in the relatively near future. It is usually recommended that the child not sleep in the same bed with anyone else for a period of time, and if you are remaining at a Ronald McDonald house (or similar) the hospital may send sheets with you to use until you are discharged to go home. Children must generally wait another week or so to return to school, and should eat off disposable plates and use disposable silverware for a couple of weeks after treatment.

Follow-up after Treatment

After the treatment, children continue to take SSKI (potassium iodide) drops for quite a while. They will also have blood counts checked regularly and will probably require some transfusions as MIBG has a significant effect on bone marrow. Parents have reported that counts fell 3-6 weeks after the treatment. One parent said their child needed GCSF shots to boost white counts for a month; another mentioned that it took 3 months for her child's platelets to get to 75. Stem cells may be needed or required as part of the protocol, depending on the dosage of MIBG and whether or not there is more than one round of treatment. Getting the stem cells back is very easy, much like a platelet transfusion.

Follow up will continue until the counts are back up, and will also include follow up scans. The effects MIBG therapy has had on tumor burden can take several weeks to show up on scans, and the doctors may have your child do more than one scan to verify the impact of the treatment.

Overall, most parents say that, despite their prior anxieties, MIBG therapy is relatively easy and entails only minor inconveniences and manageable side effects. As one parent opined, MIBG treatment is "rather a dull affair," and another summed it up as follows: "It all seems scary and overwhelming, but it's actually quite a simple treatment. It's just a boring few days and then it's over."

Please contact info@cncfhope.org with any comments

¹ <http://www.nant.org/nant2004-06.php>

² <http://www.nant.org/nant2007-01.php>