

# **Coping with 8H9 Intrathecal Antibodies**

## What is Intrathecal 8H9 Antibody Treatment?

Intrathecal 8H9 antibody treatment is one part of a multi-modal protocol that also uses chemotherapy, surgery, and radiation to treat neuroblastoma relapses in the brain and central nervous system (CNS). The protocol, developed at Memorial Sloan-Kettering Cancer Center (MSKCC), employs a relatively new application of 8H9 that has only been in use at MSKCC since 2003.

The antibodies themselves are radiolabeled—i.e. liquid radiation is attached to them. Radiolabeled antibodies deliver radiation specifically to any neuroblastoma cells that remain after the surgery, chemotherapy and radiation therapies.

#### What does Intrathecal mean?

The term intrathecal refers to fluid filled space between the thin layers of tissue that cover brain and spinal cord known as the cerebrospinal fluid. The 8H9 antibody is injected directly into this fluid through an Ommaya Reservoir placed in the child's head for this purpose. Once the 8H9 is injected the central nervous system is bathed in cancer-killing antibodies and radiation.

## What is an Ommaya Reservoir?

The Ommaya Reservoir is a port placed under the scalp that has a catheter threaded down to a ventricle in the brain to provide access to the spinal fluid for treatment and testing. The Ommaya is placed by a neurosurgeon and placement requires a post-surgery overnight hospital stay. The Ommaya Reservoir is accessed with a thin needle with tubing attached. A syringe is then attached to the tubing to push medication in or draw spinal fluid samples out. Because the port protrudes a little above the skull it looks like a bump, but for the most part it is invisible when the child has hair. Ommaya Reservoirs require no maintenance; they do not need to be cleaned or flushed.

#### How 8H9 antibody treatments administered?

Each treatment consists of two doses, a test dose and then the therapeutic dose, given exactly one week apart. If the therapeutic dose is delayed for any reason (e.g. low counts), it must be given within two weeks of the test dose or the test dose must be repeated.

Children are admitted to the hospital the day before the dose is given. The Ommaya Reservoir is accessed just before the 8H9 is administered and must remain accessed for about 90 minutes. The injection into the Ommaya is given and samples of the fluid are taken from it at specified intervals for one hour after the injection. The test and the therapeutic treatments are administered the same way except that the dose of the 8H9 antibody is doubled and the Radiation Officer is present during the therapeutic injection.

Scans are performed at 24 and 48 hours after the injection on the same machine used for MIBG scans. The child is usually discharged from the hospital after the 24 hours post-injection scan.

#### What are the side effects?

The good news is that some children have had no side effects at all. Others have been observed to experience some or all of the following: fever, nausea, a tingling sensation lasting a few minutes, or

lowered counts requiring transfusions in the months following the treatment. Please note that this is not meant to be a complete list of possible side effects, just what has been observed by a few parents.

Because of the radiation level in the child's body after the therapeutic dose, it is recommended that the child stay several feet away from other children and women who are pregnant or considering future pregnancies for a few days after treatment.

# **Coping with Treatment and Side Effects**

You will learn a lot about how your child reacts to the intrathecal 8H9 antibody treatment after the first test dose. Many parents find that with this knowledge, the therapeutic treatment is much easier for their child because they know what side effects are most likely. For example, if a child experiences a very high fever during the test dose, parents can request Tylenol before the therapeutic dose and every four hours after even if there is no evidence of fever. Similar arrangements can be made for the provision of anti-nausea drugs if nausea is an expected side effect.

Families considering future pregnancies should plan, if possible, to have Dad stay overnight at the hospital after the therapeutic dose. Although mothers may be uncomfortable leaving their child for the night, it is probably better to have my Dad stay with the child than to be limited to providing comfort at arm's length.

Although accessing the Ommaya Reservoir is said to be painless, children generally don't like it. One child finds it tolerable if EMLA is placed on the port before access, but others find it extremely upsetting. The idea of having a needle put into their head is very frightening and may make children very angry. One child coped by using his dinosaur puppet to "bite" the doctors, who were all good sports about it.

Ommaya taps are a part of routine check-ups after 8H9 treatment, but they last only a few minutes. One Mom reported that after a tap her child felt tired and dizzy and would sleep for a while but felt better by evening. It may be possible to request that the routine taps be performed while the child is under anesthesia for bone marrow biopsies to spare additional trauma and emotional stress.

Please contact *info@cncfhope.org* with any comments