

Caring for Yourself After Your Neuroblastoma Vaccines

This information explains how to care for yourself after your neuroblastoma vaccine at Memorial Sloan Kettering (MSK).

For the rest of this resource, the words “you” and “your” refer to you or your child.

About Your Neuroblastoma Vaccines

As part of your cancer treatment, you will have 7 neuroblastoma vaccine injections (shots). This treatment is still being developed but is meant to train your body to fight cancer cells. You and your doctor will go over your injection schedule together.

You may have some side effects after each of your injections. Most side effects usually go away after a few hours, but some may last up to several days.

Common Side Effects

Pain

The most common side effect of the injections is pain. You may feel a burning sensation and soreness around your injection site. While you may feel this at the time of your injection, you may also have some pain days after your injection. The amount of pain felt is different for everyone.

Managing your pain

Some ways of relieving pain can affect your treatment. Follow these guidelines when managing your pain.

- Move the arm or leg where you got the injection. This can help reduce your pain.
- You will get a prescription for pain medication. You can take this medication to help manage your pain.
 - Don't take any other medications to relieve pain unless your healthcare provider says it's okay. This includes both prescription and over-the-counter (medications you buy without a prescription) medications. Some pain medications, such as acetaminophen (Tylenol®), ibuprofen (Advil® or Motrin®), or aspirin, can affect your treatment.
- Don't apply warm or cold packs to your injection site before or after your injection.
- Don't use numbing cream, such as lidocaine cream (EMLA® and LMX®), before or after your injection.
- Don't use "freezing spray", such as ethyl chloride, before or after your injection.

Allergic reactions

You may have an allergic reaction to the neuroblastoma vaccine. The allergic reaction may cause hives, redness, or swelling of the skin around your injection site. These reactions can happen at any time during your treatment and will go away on their own.

Managing your allergic reaction

- Your healthcare provider will give you a prescription for allergy medication. Make sure you have the medication with you before you leave the hospital.
- Don't take any allergy medication, such as hydroxyzine (Vistaril®) or diphenhydramine (Benadryl®), for allergic reactions unless your healthcare provider says it's okay.
- Don't take any steroids, such as hydrocortisone (Cortizone-10®), for allergic reactions unless your healthcare provider says it's okay.
- If the hives, redness, or swelling don't go away after taking allergy medication, call your healthcare provider.

Call 911 if you have difficulty breathing or your lips, tongue, or throat become swollen.

Fever

You may have a fever of 100.4° F (38 ° C) or higher, after your injection. The fever may be related to the vaccine or a sign of infection. If you have a fever, call your healthcare provider for more instructions.

Central venous catheter infections

Central venous catheters (CVC), such as central lines, can collect bacteria and cause infection. If you have a cvc and have a fever or redness, swelling, or tenderness at the catheter site during your neuroblastoma vaccine injections, call your healthcare provider right away.

Beta Glucan Instructions

Your nurse will give you beta glucan to take at home. Beta glucan is a sugar that can help your body fight cancer cells. The beta glucan is a liquid that you swallow. You will start taking beta glucan after your third injection.

Things to remember

- Take beta glucan on an empty stomach. For 1 hour before and after you take it, don't eat or drink anything except the things listed below.
 - You may take beta glucan with small sips of water, if you need to.
 - If you feel nauseous, you may eat hard candy or lollipops with beta glucan.
- Your nurse will give you a diary to keep track of your beta glucan doses. Write down the time you took beta glucan and any side effects you have. Remember to give your log to your healthcare provider or research nurse when you return to clinic.

Call 911 if You Have:

- Trouble breathing

- Swelling of your lips, tongue, or throat

Call Your Healthcare Provider if You Have:

- A fever of 100.4° F (38 ° C) or higher
- A CVC and have a fever, redness, swelling, or tenderness at your catheter site
- If you still have pain after 3 days
- Any questions or concerns

Contact Information

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 8:00 AM to 6:00 PM at the numbers below.

Healthcare Provider: _____

Phone number: _____

After 6:00 PM, during the weekend, and on holidays, call 212-639-2000 and ask to talk with the pediatric fellow on call.

Urgent Care Center

You may need to go to MSK's Pediatric Urgent Care Center (UCC) depending on the issue you're experiencing. The Pediatric UCC is located on the 9th floor of Memorial Hospital (MSK's main hospital).

The closest entrance is located at 1275 on 68th street and York Avenue. This entrance is open 24 hours a day, 7 days a week. Once you're in the hospital, take the M elevators to the 9th floor. Check in at the M9 front desk.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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