PATIENT & CAREGIVER EDUCATION

Caring for Yourself After Your Neuroblastoma Vaccines

This information explains how to care for yourself after your neuroblastoma vaccine at 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 8 or 10 neuroblastoma vaccine injections (shots). This treatment is experimental, which means it is still being tested. You may be having it if you joined a research study, also called a clinical trial. This treatment is meant to help train your body to fight cancer cells. You and your healthcare provider 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 is pain. You may have a burning feeling and soreness in the area where you had your injection. You may feel this when you get your injection, or days later. Everyone feels a different amount of pain.

Managing your pain

Some ways of managing 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.
- Do not take any other medicines to ease pain unless your healthcare provider says it's OK. This includes both prescription and over-the-counter (medicines you buy without a prescription) medicines. Some pain medicines, such as acetaminophen (Tylenol®), ibuprofen (Advil® or Motrin®), or aspirin, can affect your treatment.
- Do not apply warm or cold packs to your injection site before or after you get your injection.
- Do not use numbing cream, such as lidocaine cream (EMLA® and LMX ®), before or after you get your injection.
- Do not use "freezing spray," such as ethyl chloride, before or after you get your injection.

Allergic reactions

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

Managing your allergic reaction

- Do not take any allergy medicine, such as hydroxyzine (Vistaril®) or diphenhydramine (Benadryl®), for allergic reactions unless your healthcare provider says it's OK.
- Do not take any steroids, such as hydrocortisone (Cortizone-10®), for allergic reactions unless your healthcare provider says it's OK.
- If the hives, redness, or swelling don't go away after taking allergy medicine, 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 after your treatment. The fever may be related to treatment or a sign of infection. You should make sure you have a thermometer at home. It's important to call your healthcare provider for instructions if you have:
- A fever of 100.4° F (38°C) to 100.9 ° F (38.2°C) that lasts for longer than 1 hour.
- A fever of 101°F (38.3°C) or higher.

Central venous catheter infections

A central line, or central venous catheter, is like an artificial vein. It will make it easier for your care team to access your blood vessels for medicines and tests. Central lines can collect bacteria and cause infection. You may have a fever, redness, swelling, or tenderness at the catheter site. Call your healthcare provider right away if you have any of these symptoms.

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. Your nurse will provide you with the beta glucan schedule.

Your nurse will also give you a diary to keep track of your beta glucan doses. Try to take the beta glucan at the same time every day. Write down any side effects you had in the comments section of your diary. Remember to give your log to your healthcare provider or research nurse when you return to clinic.

If a dose is spilled, or you throw it up, do not take another dose. Write what happened in the comments section of your diary.

You must store beta glucan bottles in the fridge, especially after a bottle has been opened. If you will be flying, carry the beta glucan in your carry-on bag. An

airplane letter will be provided for you.

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 (feeling like you're going to throw up), you may eat hard candy or lollipops with beta glucan.

Sargramostim

If you are receiving Sargramostim (GM-CSF) as part of this study, read the information below:

- If you are in Group 2, you will give yourself a GM-CSF injection under your skin every day for 3 to 7 days around each vaccination. Your study team will tell you exactly when to give the instructions.
- For more information, read *How To Give Your Child a Sargramostim (Leukine®) Injection* (www.mskcc.org/pe/leukine)

Call your healthcare provider if you have:

- A fever of 100.4° F (38°C) to 100.9 ° F (38.2°C) that lasts for longer than 1 hour.
- A fever of 101°F (38.3°C) or higher.
- Signs or symptoms of possible infection such as pale skin, sweating, or chills.
- A CVC and have a fever, redness, swelling, or tenderness at your catheter site.
- Pain after 3 days.
- Any questions or concerns.

Contact information

If you have any questions, contact a member of your care team directly. You can reach them Monday through Friday from 8 a.m. to 6 p.m.

If you need to reach a pediatric fellow after 5 p.m., during the weekend, or on a holiday, call 212-639-2000.

Urgent care center

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

The closest entrance is located at 1275 York Avenue (at E. 68th Street). This entrance is always open. Once you're in the hospital, take the M elevators to the 9th floor. Check in at the M9 front desk

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

Go to the UCC or call 911 if you have:

- Trouble breathing.
- Shortness of breath.
- Redness, swelling, or tenderness at the catheter site.
- Swelling of your lips, tongue, or throat.

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

Caring for Yourself After Your Neuroblastoma Vaccines - Last updated on July 24, 2026
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