- Why do you think my child has neuroblastoma?
- Is there a chance my child doesn't have neuroblastoma?
- What will happen next?

How does the doctor know my child has neuroblastoma?

Neuroblastomas are often found when a child is brought to the doctor because of certain <u>signs or symptoms</u>². (Some neuroblastomas are first seen on an ultrasound done during pregnancy, even before a child is born.)

If signs or symptoms are pointing to neuroblastoma, <u>tests</u>³ will be done. Here are some of the tests your child may need:

Blood and urine tests

Chemicals that may show neuroblastoma can be found in certain blood and urine tests. Other tests may also be done to check how the liver, kidneys, and other organs are working.

Imaging tests

- Ultrasound (sonogram): An ultrasound may be one of the first tests done if the doctor thinks a child has a neuroblastoma. An ultrasound can be used to look for problems in the abdomen, but it can't be used to look at the chest or neck.
- Chest or other x-ray: An x-ray may be one of the first imaging tests done if a child has symptoms, although it can't always show a tumor.
- **MRI:** An MRI can show more details about some parts of the body. It is helpful for seeing the extent of a tumor. This test does not use radiation.
- **CT scan:** CT scans (sometimes called CAT scans) use x-rays to make detailed pictures of the inside of the body. This test can help tell if the neuroblastoma has spread outside of the nervous system.
- **MIBG scan:** A MIBG scan is usually done after a CT or MRI to see how far a neuroblastoma has spread. This scan uses a dye that attaches to neuroblastoma cells, and a special camera to take pictures of where the dye is in the body.
- **Bone scan:** A bone scan uses a different dye to look at all the bones in the body. If a MIBG scan is done, this test might not be needed.
- PET scan: A PET scan uses a dye and a camera, too. The pictures a PET scan

takes are not as detailed as a CT or MRI scan. But a PET scan can help find neuroblastoma cells almost anywhere in the body.

Biopsies

- **Surgical biopsy:** For this test, the doctor removes a piece of the tumor. The sample is then sent to the lab and looked at for cancer cells. Other lab tests might be done if cancer cells are found.
- Bone marrow aspiration and biopsy: This test might be done to see if neuroblastoma has spread to the bone marrow (the soft, inner parts of some bones). A doctor uses thin, hollow needles to remove small amounts of bone marrow, usually from the hip bone. The samples are sent to a lab to check them for cancer cells.

How serious is my child's neuroblastoma?

Children with neuroblastoma are divided into <u>risk groups</u>⁴, based on things like the child's age, how far the cancer has grown or spread, and if the cancer cells have certain gene changes. The risk group helps doctors decide which treatment options are best. Ask the doctor to explain which risk group your child might be in and what it means for their outlook and treatment.

Questions to ask the doctor

- Which neuroblastoma risk group is my child in? What does this mean?
- Are there any other factors that might affect my child's outlook?
- Will we will need to see other doctors?
- How much experience do you have treating neuroblastoma?
- Will my child need any other tests?
- Who will do these tests?
- Where will they be done?
- How and when will we get the results?
- Who will explain the results?
- Does the tumor need to be treated? If so, how soon do we need to start treatment?
- What will happen next?

What kind of treatment will my child need?

The <u>treatment⁵ plan that's best for your child will depend on:</u>

- The risk group of the neuroblastoma
- The chance that a type of treatment will help
- Your feelings about the treatment and the side effects that could come with it

Surgery

<u>Surgery</u>⁶ to remove the tumor may be the only treatment needed for small neuroblastomas. If neuroblastomas are large or if they have spread, other treatment will

chemo side effects, so be sure to talk to your child's cancer care team so they can help.

Immunotherapy

<u>Immunotherapy</u>⁸ drugs are newer treatments that help the immune system attack the cancer. Some are now being used to treat high-risk neuroblastomas. Many others are now being studied as well.

Retinoid therapy

<u>Retinoids</u>⁹ are chemicals that are like vitamin A. Sometimes a retinoid drug is given after other treatment for neuroblastoma. Talk to your child's doctor to know if this kind of treatment may help with your child's neuroblastoma.

Radiation treatments

External beam radiation

<u>Radiation</u>¹⁰ uses high-energy rays (like x-rays) to kill cancer cells. Most children with neuroblastoma don't need radiation, but some might, depending on their risk group. Ask your child's doctor if radiation will be part of the treatment and what to expect. **Side effects of external radiation**

If your child's doctor suggests radiation treatment, ask about what side effects might happen. Side effects depend on where the radiation is aimed. The most common side effects of radiation are:

- Skin changes in the area where the radiation is given
- Feeling very tired

These side effects tend to get better after treatment ends. Radiation can also cause long-term effects if it reaches the brain, heart, lungs, or other organs. Talk to your child's cancer care team about what to expect.

MIBG radiotherapy

MIBG therapy is a kind of radiation therapy. It uses a chemical with radiation attached to it, which is injected into the blood to treat neuroblastoma.

Side effects of MIBG

cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

- 1. www.cancer.org/cancer/types/neuroblastoma/about/what-is-neuroblastoma.html
- 2. <u>www.cancer.org/cancer/types/neuroblastoma/detection-diagnosis-staging/signs-and-symptoms.html</u>
- 3. <u>www.cancer.org/cancer/types/neuroblastoma/detection-diagnosis-staging/how-diagnosed.html</u>
- 4. <u>www.cancer.org/cancer/types/neuroblastoma/detection-diagnosis-staging/risk-groups.html</u>
- 5. www.cancer.org/cancer/types/neuroblastoma/treating.html
- 6. www.cancer.org/cancer/types/neuroblastoma/treating/surgery.html
- 7. <u>www.cancer.org/cancer/types/neuroblastoma/treating/chemotherapy.html</u>
- 8. www.cancer.org/cancer/types/neuroblastoma/treating/immunotherapy.html
- 9. www.cancer.org/cancer/types/neuroblastoma/treating/retinoid-therapy.html
- 10. www.cancer.org/cancer/types/neuroblastoma/treating/radiation-therapy.html
- 11. <u>www.cancer.org/cancer/types/neuroblastoma/treating/high-dose-chemo-</u> radiation.html
- 12. <u>www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-</u> trials.html
- 13. <u>www.cancer.org/cancer/types/neuroblastoma/after-treatment/follow-up.html</u>
- 14. <u>www.cancer.org</u>

Words to know

Biopsy (BY-op-see): Taking out a small piece of body tissue to see if there are cancer cells in it.

Chemotherapy (KEY-mo-THAIR-uh-pee) or chemo (KEY-mo): The use of drugs to kill cancer cells.

Immune system: The body system that fights infection.

Immunotherapy (IM-yuh-no-THAIR-uh-pee): Treatments that uses the body's immune system to fight cancer.

Malignant (muh-LIG-nunt): Having cancer in it.

Metastasis (muh-TAS-tuh-sis): The spread of cancer cells from where they started to other places in the body.

Neurons: Nerve cells, or the main cells that make up the nervous system.

Pediatric oncologist (pee-dee-AT-trick on-KAHL-uh-jist): A doctor who treats children who have cancer.

Radiation (RAY-dee-AY-shun): A type of treatment that uses high-energy rays (like x-rays) to kill cancer cells.

Retinoids (ret-uh-noyds): Vitamin A and man-made medicines similar to vitamin A, some of which can be used to treat neuroblastoma.

How can I learn more?

cancer.org | 1.800.227.2345