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Childhood Central Nervous System Germ Cell Tumors Treatment (PDQ®)

Patient Version

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This PDQ cancer information summary has current information about the treatment of childhood central nervous system germ cell tumors. It is meant to inform and help patients, families, and caregivers. It does not give formal guidelines or recommendations for making decisions about health care.

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General Information About Childhood Central Nervous System (CNS) Germ Cell Tumors

Key Points for This Section

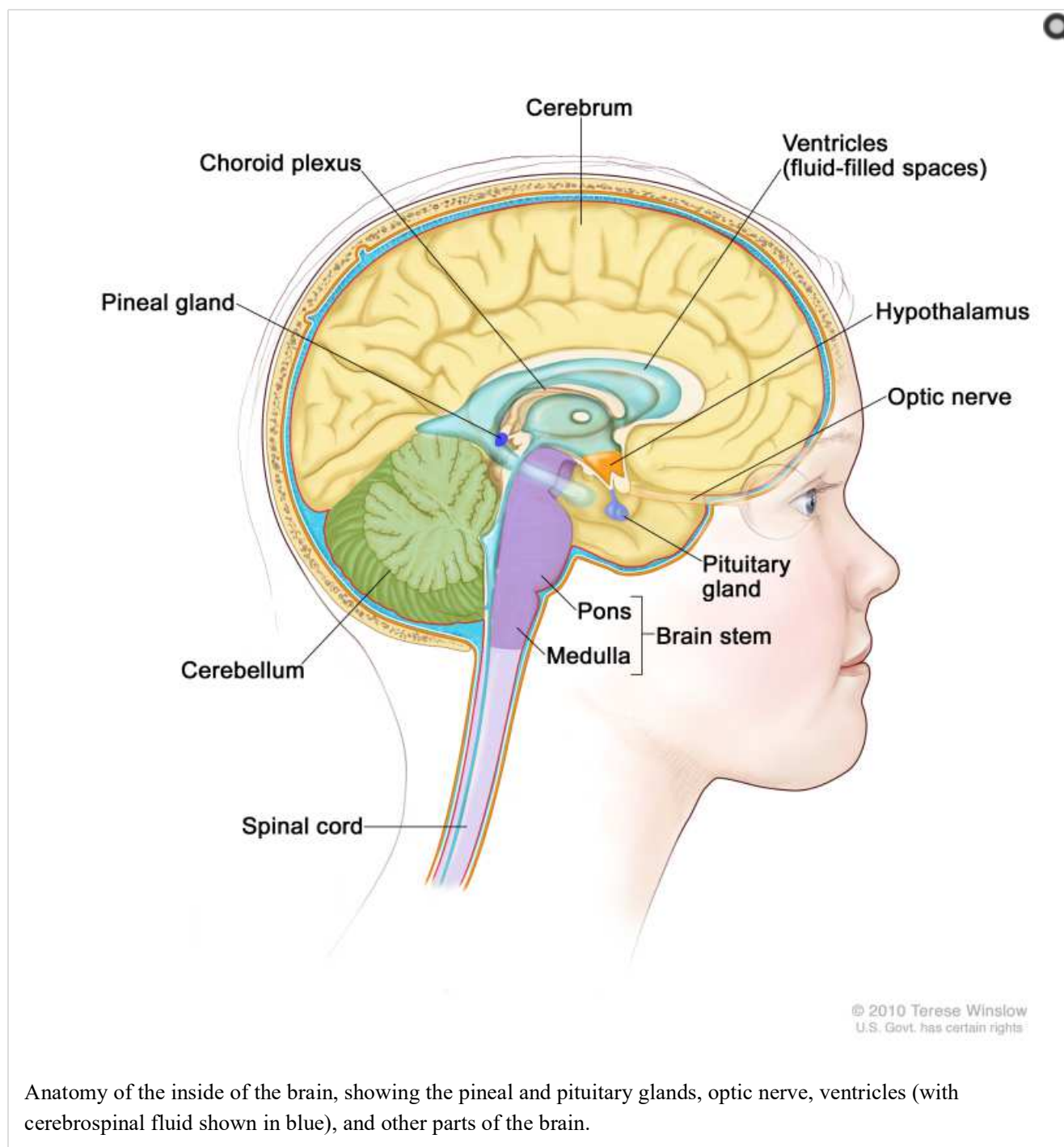
- Childhood central nervous system (CNS) germ cell tumors form from germ cells.
- There are different types of childhood CNS germ cell tumors.
 - Germinomas
 - Nongerminomas
 - Teratomas
- The cause of most childhood CNS germ cell tumors is not known.
- Signs and symptoms of childhood CNS germ cell tumors include unusual thirst, frequent urination, or vision changes.
- Imaging studies and other tests are used to help diagnose childhood CNS germ cell tumors.
- A biopsy may be done to be sure of the diagnosis of a CNS germ cell tumor.
- Certain factors affect prognosis (chance of recovery).

Childhood central nervous system (CNS) germ cell tumors form from germ cells.

Germ cells are special types of cells that are present as the fetus (unborn baby) develops. These cells usually become sperm in the testicles or unfertilized eggs in the ovaries as the child matures. Most germ cell tumors form in the testes or ovaries. Sometimes the germ cells travel to or from other parts of the fetus as it develops and later become germ cell tumors. Germ cell tumors that form in the brain or spinal cord are called CNS (central nervous system) germ cell tumors.

CNS germ cell tumors occur most often in patients aged 10 to 19 years and more often in males than in females. The most common places for one or more CNS germ cell tumors to form is in the brain near the pineal gland and in an area of the brain that includes the pituitary gland and the tissue just above it. Sometimes germ cell tumors form in other

areas of the brain.



Anatomy of the inside of the brain, showing the pineal and pituitary glands, optic nerve, ventricles (with cerebrospinal fluid shown in blue), and other parts of the brain.

This summary is about germ cell tumors that start in the central nervous system (brain and spinal cord). Germ cell tumors may also form in other parts of the body. See the PDQ summary on [Childhood Extracranial Germ Cell Tumors Treatment](#) for information on germ cell tumors that are extracranial (outside the brain).

CNS germ cell tumors usually occur in children but may occur in adults. Treatment for children may be different than treatment for adults. See the following PDQ summaries for information about treatment for adults:

- [Adult Central Nervous System Tumors Treatment](#)
- [Extragenadal Germ Cell Tumors Treatment](#)

For information about other types of childhood brain and spinal cord tumors, see the PDQ summary on [Childhood Brain and Spinal Cord Tumors Treatment Overview](#).

There are different types of childhood CNS germ cell tumors.

Different types of CNS germ cell tumors can form from the special cells that later become sperm or unfertilized eggs. The type of CNS germ cell tumor that is diagnosed depends on what the cells look like under a microscope and results of laboratory tests that check tumor marker levels.

This summary is about the treatment of several types of CNS germ cell tumors.

Germinomas

Germinomas are the most common type of CNS germ cell tumor and have a good prognosis. Tumor marker levels are not used to diagnose germinomas.

Nongerminomas

Some nongerminomas make hormones, such as alpha-fetoprotein (AFP) and beta-human chorionic gonadotropin (beta-hCG). Types of nongerminomas include the following:

- Embryonal carcinomas make the hormones AFP and beta-hCG.
- Yolk sac tumors make the hormone AFP.
- Choriocarcinomas make the hormone beta-hCG.
- Mixed germ cell tumors are made of more than one kind of germ cell. They may make AFP and beta-hCG.

Teratomas

CNS teratomas are described as mature or immature, based on how normal the cells look under a microscope. Mature teratomas look almost like normal cells under a microscope and are made of different kinds of tissue, such as hair, muscle, and bone. Immature teratomas look very different from normal cells under a microscope and are made of cells that look like fetal cells. Some immature teratomas are a mix of mature and immature cells. Tumor marker levels are not used to diagnose teratomas.

The cause of most childhood CNS germ cell tumors is not known.

Signs and symptoms of childhood CNS germ cell tumors include unusual thirst, frequent urination, or vision changes.

Signs and symptoms depend on the following:

- Where the tumor has formed.
- The size of the tumor.
- Whether the tumor or the body make too much of certain hormones.

Signs and symptoms may be caused by childhood CNS germ cell tumors or by other conditions. Check with your child's doctor if your child has any of the following:

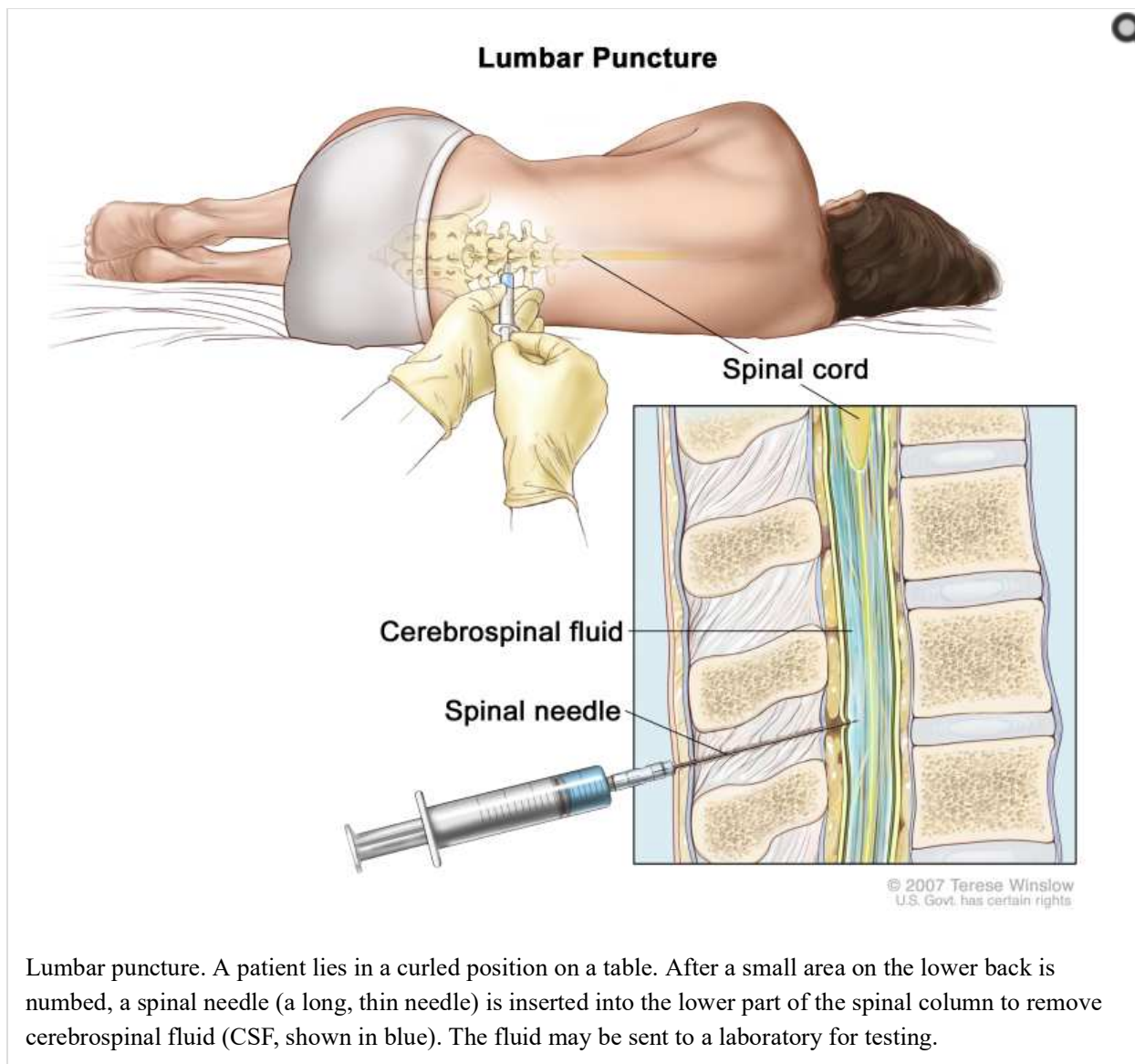
- Being very thirsty.
- Making large amounts of urine that is clear or almost clear.
- Frequent urination.
- Bed wetting or getting up at night to urinate.
- Trouble moving the eyes, trouble seeing clearly, or seeing double.
- Loss of appetite.
- Weight loss for no known reason.
- Early or late puberty.

- Short stature (being shorter than normal).
- Headaches.
- Nausea and vomiting.
- Feeling very tired.
- Having problems with school work.

Imaging studies and other tests are used to help diagnose childhood CNS germ cell tumors.

The following tests and procedures may be used:

- **Physical exam and health history:** An exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual. A history of the patient's health habits and past illnesses and treatments will also be taken.
- **Neurological exam:** A series of questions and tests to check the brain, spinal cord, and nerve function. The exam checks a person's mental status, coordination, and ability to walk normally, and how well the muscles, reflexes, and senses work. This may also be called a neuro exam or a neurologic exam.
- **Visual field exam:** An exam to check a person's field of vision (the total area in which objects can be seen). This test measures both central vision (how much a person can see when looking straight ahead) and peripheral vision (how much a person can see in all other directions while staring straight ahead). The eyes are tested one at a time. The eye not being tested is covered.
- **MRI (magnetic resonance imaging) with gadolinium:** A procedure that uses a magnet, radio waves, and a computer to make a series of detailed pictures of areas inside the brain and spinal cord. A substance called gadolinium is injected into a vein. The gadolinium collects around the cancer cells so they show up brighter in the picture. This procedure is also called nuclear magnetic resonance imaging (NMRI).
- **Lumbar puncture:** A procedure used to collect cerebrospinal fluid (CSF) from the spinal column. This is done by placing a needle between two bones in the spine and into the CSF around the spinal cord and removing a sample of the fluid. The sample of CSF is checked under a microscope for signs of tumor cells and tested for tumor markers. The amount of protein and glucose in the sample may also be tested. A higher than normal amount of protein or lower than normal amount of glucose may be a sign of a tumor. This procedure is also called an LP or spinal tap.



- **Tumor marker tests:** A procedure in which a sample of blood or cerebrospinal fluid (CSF) is checked to measure the amounts of certain substances released into the blood and CSF by organs, tissues, or tumor cells in the body. Certain substances are linked to specific types of cancer when found in increased levels in the blood. These are called tumor markers.

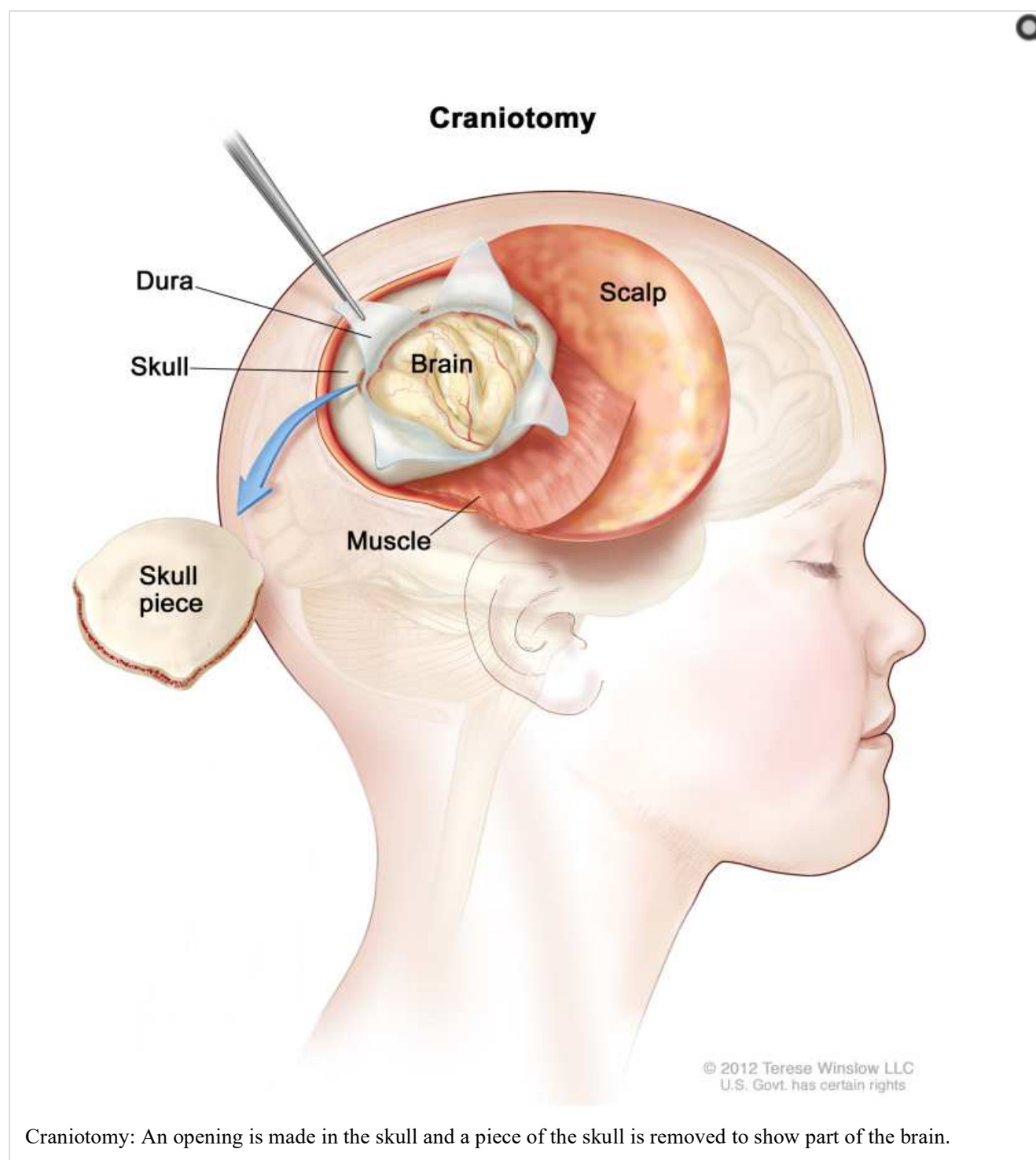
The following tumor markers are used to diagnose some CNS germ cell tumors:

- Alpha-fetoprotein (AFP).
 - Beta-human chorionic gonadotropin (beta-hCG).
- **Blood chemistry studies:** A procedure in which a blood sample is checked to measure the amounts of certain substances released into the blood by organs and tissues in the body. An unusual (higher- or lower-than-normal) amount of a substance can be a sign of disease.
 - **Blood hormone studies:** A procedure in which a blood sample is checked to measure the amounts of certain hormones released into the blood by organs and tissues in the body. An unusual (higher- or lower-than-normal) amount of a substance can be a sign of disease in the organ or tissue that makes it. The blood will be checked for the levels of hormones made by the pituitary gland and other glands.

A biopsy may be done to be sure of the diagnosis of a CNS germ cell tumor.

If doctors think your child may have a CNS germ cell tumor, a biopsy may be done. For brain tumors, the biopsy is done by removing part of the skull and using a needle to remove a sample of tissue. Sometimes, a needle guided by a

computer is used to remove the tissue sample. A pathologist views the tissue under a microscope to look for cancer cells. If cancer cells are found, the doctor may remove as much tumor as safely possible during the same surgery. The piece of skull is usually put back in place after the procedure.



The following test may be done on the sample of tissue that is removed:

- **Immunohistochemistry:** A laboratory test that uses antibodies to check for certain antigens (markers) in a sample of a patient's tissue. The antibodies are usually linked to an enzyme or a fluorescent dye. After the antibodies bind to a specific antigen in the tissue sample, the enzyme or dye is activated, and the antigen can then be seen under a microscope. This type of test is used to help diagnose cancer and to help tell one type of cancer from another type of cancer.

Sometimes the diagnosis can be made based on the results of imaging and tumor marker tests and a biopsy is not needed.

Certain factors affect prognosis (chance of recovery).

The prognosis depends on the following:

- The type of germ cell tumor.
- The type and level of any tumor markers.
- Where the tumor is in the brain or in the spinal cord.
- Whether the cancer has spread within the brain and spinal cord or to other parts of the body.
- Whether the tumor is newly diagnosed or has recurred (come back) after treatment.

Stages of Childhood CNS Germ Cell Tumors

Key Points for This Section

- Childhood central nervous system (CNS) germ cell tumors rarely spread outside of the brain and spinal cord.
- Sometimes childhood central nervous system germ cell tumors come back after treatment.

Childhood central nervous system (CNS) germ cell tumors rarely spread outside of the brain and spinal cord.

The process used to find out how much cancer there is and whether the cancer has spread is called staging. There is no standard staging system for childhood central nervous system (CNS) germ cell tumors.

The treatment plan depends on the following:

- The type of germ cell tumor.
- Whether the tumor has spread within the brain and spinal cord or to other parts of the body, such as the lung or bone.
- The results of tests and procedures done to diagnose childhood CNS germ cell tumors.
- Whether the tumor is newly diagnosed or has recurred (come back) after treatment.

Sometimes childhood central nervous system germ cell tumors come back after treatment.

The tumors usually recur (come back) where they first formed. The tumors may also come back in other places and/or in the meninges (thin layers of tissue that cover and protect the brain and spinal cord).

Treatment Option Overview

Key Points for This Section

- There are different types of treatment for patients with childhood central nervous system (CNS) germ cell tumors.
- Children with childhood CNS germ cell tumors should have their treatment planned by a team of health care providers who are experts in treating cancer in children.
- Four types of treatment are used:
 - Radiation therapy
 - Chemotherapy

- Surgery
- High-dose chemotherapy with stem cell rescue
- New types of treatment are being tested in clinical trials.
- Treatment for childhood CNS germ cell tumors may cause side effects.
- Patients may want to think about taking part in a clinical trial.
- Patients can enter clinical trials before, during, or after starting their cancer treatment.
- Follow-up tests may be needed.

There are different types of treatment for patients with childhood central nervous system (CNS) germ cell tumors.

Different types of treatment are available for children with childhood central nervous system (CNS) germ cell tumors. Some treatments are standard (the currently used treatment), and some are being tested in clinical trials. A treatment clinical trial is a research study meant to help improve current treatments or obtain information on new treatments for patients with cancer. When clinical trials show that a new treatment is better than the standard treatment, the new treatment may become the standard treatment.

Because cancer in children is rare, taking part in a clinical trial should be considered. Some clinical trials are open only to patients who have not started treatment.

Children with childhood CNS germ cell tumors should have their treatment planned by a team of health care providers who are experts in treating cancer in children.

Treatment will be overseen by a pediatric oncologist and/or a radiation oncologist. A pediatric oncologist is a doctor who specializes in treating children with cancer. A radiation oncologist specializes in treating cancer with radiation therapy. These doctors work with other pediatric health care providers who are experts in treating children with childhood CNS germ cell tumors and who specialize in certain areas of medicine. These may include the following specialists:

- Pediatrician.
- Pediatric neurosurgeon.
- Neurologist.
- Endocrinologist.
- Ophthalmologist.
- Pediatric nurse specialist.
- Rehabilitation specialist.
- Psychologist.
- Social worker.

Four types of treatment are used:

Radiation therapy

Radiation therapy is a cancer treatment that uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing.

External radiation therapy uses a machine outside the body to send radiation toward the area of the body with cancer. Certain ways of giving radiation therapy can help keep radiation from damaging nearby healthy tissue. This type of

radiation therapy may include the following:

- **Stereotactic radiosurgery:** Stereotactic radiosurgery is a type of external radiation therapy. A rigid head frame is attached to the skull to keep the head still during the radiation treatment. A machine aims a single large dose of radiation directly at the tumor. This procedure does not involve surgery. It is also called stereotaxic radiosurgery, radiosurgery, and radiation surgery.

The way the radiation therapy is given depends on the type of cancer being treated.

Radiation therapy to the brain can affect growth and development in young children. Certain ways of giving radiation therapy can lessen the damage to healthy brain tissue. For children younger than 3 years, chemotherapy may be given instead. This can delay or reduce the need for radiation therapy.

Chemotherapy

Chemotherapy is a cancer treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. When chemotherapy is taken by mouth or injected into a vein or muscle, the drugs enter the bloodstream and can reach cancer cells throughout the body (systemic chemotherapy).

Surgery

Whether surgery to remove the tumor can be done depends on where the tumor is in the brain. Surgery to remove the tumor may cause severe, long-term side effects.

Surgery may be done to remove teratomas and may be used for germ cell tumors that come back. After the doctor removes all the cancer that can be seen at the time of the surgery, some patients may be given chemotherapy or radiation therapy after surgery to kill any cancer cells that are left. Treatment given after the surgery, to lower the risk that the cancer will come back, is called adjuvant therapy.

High-dose chemotherapy with stem cell rescue

High doses of chemotherapy are given to kill cancer cells. Healthy cells, including blood-forming cells, are also destroyed by the cancer treatment. Stem cell transplant is a treatment to replace the blood-forming cells. Stem cells (immature blood cells) are removed from the blood or bone marrow of the patient or a donor and are frozen and stored. After the patient completes chemotherapy, the stored stem cells are thawed and given back to the patient through an infusion. These reinfused stem cells grow into (and restore) the body's blood cells.

New types of treatment are being tested in clinical trials.

This summary section describes treatments that are being studied in clinical trials. It may not mention every new treatment being studied. Information about clinical trials is available from the NCI website.

Targeted therapy

Targeted therapy is a type of treatment that uses drugs or other substances to identify and attack specific cancer cells. Targeted therapies usually cause less harm to normal cells than chemotherapy or radiation therapy do.

Targeted therapy is being studied for the treatment of childhood CNS germ cell tumors that have recurred (come back).

Treatment for childhood CNS germ cell tumors may cause side effects.

For information about side effects that begin during treatment for cancer, see our Side Effects page.

Side effects from cancer treatment that begin after treatment and continue for months or years are called late effects.

Late effects of cancer treatment may include the following:

- Physical problems.
- Changes in mood, feelings, thinking, learning, or memory.
- Second cancers (new types of cancer).

Some late effects may be treated or controlled. It is important to talk with your child's doctors about the possible late effects caused by some treatments. (See the [PDQ summary on Late Effects of Treatment for Childhood Cancer](#) for more information).

Patients may want to think about taking part in a clinical trial.

For some patients, taking part in a clinical trial may be the best treatment choice. Clinical trials are part of the cancer research process. Clinical trials are done to find out if new cancer treatments are safe and effective or better than the standard treatment.

Many of today's standard treatments for cancer are based on earlier clinical trials. Patients who take part in a clinical trial may receive the standard treatment or be among the first to receive a new treatment.

Patients who take part in clinical trials also help improve the way cancer will be treated in the future. Even when clinical trials do not lead to effective new treatments, they often answer important questions and help move research forward.

Patients can enter clinical trials before, during, or after starting their cancer treatment.

Some clinical trials only include patients who have not yet received treatment. Other trials test treatments for patients whose cancer has not gotten better. There are also clinical trials that test new ways to stop cancer from recurring (coming back) or reduce the side effects of cancer treatment.

Clinical trials are taking place in many parts of the country. Information about clinical trials supported by NCI can be found on NCI's [clinical trials search](#) webpage. Clinical trials supported by other organizations can be found on the [ClinicalTrials.gov](#) website.

Follow-up tests may be needed.

Some of the tests that were done to diagnose the cancer or to find out the stage of the cancer may be repeated. Some tests will be repeated in order to see how well the treatment is working. Decisions about whether to continue, change, or stop treatment may be based on the results of these tests.

Some of the tests will continue to be done from time to time after treatment has ended. The results of these tests can show if your child's condition has changed or if the cancer has recurred (come back). These tests are sometimes called follow-up tests or check-ups.

Children whose cancer affected their pituitary gland when the cancer was diagnosed will usually need to have their blood hormone levels checked. If the blood hormone level is low, replacement hormone medicine is given.

Children who had a high tumor marker level (alpha-fetoprotein or beta-human chorionic gonadotropin) when the cancer was diagnosed usually need to have their blood tumor marker level checked. If the tumor marker level increases after initial treatment, the tumor may have recurred.

Treatment of Childhood CNS Germinomas

For information about the treatments listed below, see the [Treatment Option Overview](#) section.

Treatment of newly diagnosed central nervous system (CNS) germinomas may include the following:

- Radiation therapy to the whole brain including the ventricles (fluid-filled spaces of the brain) and spinal cord. A higher dose of radiation is given to the tumor than the area around the tumor.
- Chemotherapy followed by radiation therapy.

Treatment of Childhood CNS Nongerminomas

For information about the treatments listed below, see the [Treatment Option Overview](#) section.

It is not clear what treatment is best for newly diagnosed central nervous system (CNS) nongerminomas.

Treatment of choriocarcinoma, embryonal carcinoma, yolk sac tumor, or mixed germ cell tumor may include the

following:

- [Chemotherapy](#) followed by [radiation therapy](#).
- [Surgery](#). If a mass remains after chemotherapy that continues to grow and tumor marker levels are normal (called *growing teratoma syndrome*), [surgery](#) may be needed to check if the mass is part teratoma, [fibrosis](#), or a growing tumor.
 - If the mass is a [mature teratoma](#) or fibrosis, radiation therapy is given.
 - If the mass is a growing tumor, other treatments may be given.

Treatment of Childhood CNS Teratomas

For information about the treatments listed below, see the [Treatment Option Overview](#) section.

Treatment of newly [diagnosed](#) [mature](#) and [immature](#) [central nervous system \(CNS\) teratomas](#) may include the following:

- [Surgery](#) to remove as much of the [tumor](#) as possible. If any tumor remains after surgery, more treatment may be given:
 - [Radiation therapy](#) to the tumor or [stereotactic radiosurgery](#); and/or
 - [Chemotherapy](#).

Treatment of Recurrent Childhood CNS Germ Cell Tumors

Treatment of [recurrent](#) childhood [central nervous system \(CNS\) germ cell tumors](#) may include the following:

- [Chemotherapy](#) followed by [radiation therapy](#), for germinomas.
- [High-dose chemotherapy](#) with [stem cell rescue](#) using the patient's [stem cells](#), with or without more radiation therapy, for germinomas and nongerminomas.
- A [clinical trial](#) of a new treatment.
- A [clinical trial](#) that checks a sample of the patient's [tumor](#) for certain [gene changes](#). The type of [targeted therapy](#) that will be given to the patient depends on the type of gene change.

Current Clinical Trials

Use our [clinical trial search](#) to find NCI-supported cancer clinical trials that are accepting patients. You can search for trials based on the type of cancer, the age of the patient, and where the trials are being done. [General information](#) about clinical trials is also available.

To Learn More About Childhood CNS Germ Cell Tumors

For more information about childhood central nervous system germ cell tumors, see the following:

- [Pediatric Brain Tumor Consortium \(PBTC\)](#)
- [Targeted Cancer Therapies](#)

For more childhood [cancer](#) information and other general cancer resources, see the following:

- [About Cancer](#)
- [Childhood Cancers](#)
- [CureSearch for Children's Cancer](#)
- [Late Effects of Treatment for Childhood Cancer](#)
- [Adolescents and Young Adults with Cancer](#)

- [Children with Cancer: A Guide for Parents](#)
- [Cancer in Children and Adolescents](#)
- [Staging](#)
- [Coping with Cancer](#)
- [Questions to Ask Your Doctor about Cancer](#)
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About PDQ

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Purpose of This Summary

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Clinical Trial Information

A clinical trial is a study to answer a scientific question, such as whether one treatment is better than another. Trials are based on past studies and what has been learned in the laboratory. Each trial answers certain scientific questions in order to find new and better ways to help cancer patients. During treatment clinical trials, information is collected about the effects of a new treatment and how well it works. If a clinical trial shows that a new treatment is better than one currently being used, the new treatment may become "standard." Patients may want to think about taking part in a clinical trial. Some clinical trials are open only to patients who have not started treatment.

Clinical trials can be found online at NCI's website. For more information, call the [Cancer Information Service \(CIS\)](#), NCI's contact center, at 1-800-4-CANCER (1-800-422-6237).

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