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GERM CELL TUMORS

A HANDBOOK FOR FAMILIES

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■ WHAT IS A GERM CELL TUMOR?

A *germ cell tumor* is an abnormal growth that comes from the cells of a developing ovary (in girls) or testicle (in boys). Germ cell tumors can be malignant (cancerous) or benign (noncancerous) and are made up of cells that make sperm and eggs (germ cells).

Germ cells make up the reproductive system and start growing before the baby is born. Germ cells travel toward the site where the child's testicles or ovaries will grow. In males, this is into the scrotal sac as testicular cells, and in females, into the pelvis as ovarian cells. Most often, germ cell tumors develop in the ovary or testicle, which are also called the gonads.

The most common spot for germ cell tumors to occur outside of the ovary or testicle is in the sacrococcygeal (pelvic area and tailbone), brain, abdomen (belly), neck, or chest. When germ cell tumors form outside of the gonads, they are called extragonadal.

■ WHAT ARE SOME OF THE SYMPTOMS OF A GERM CELL TUMOR?

The symptoms of a germ cell tumor depend upon their size and location. For example, if the tumor is found in the abdomen, the child's belly may appear bloated. If the tumor is in the testicle, the scrotum may be swollen, and the testicle may be enlarged or uneven in size. If the tumor is in the ovary, there may be pain, soreness, and fullness of the belly. A tumor in the pelvic area may cause constipation (irregular or difficult time passing stool), trouble with urination (peeing), or fullness of the belly. If the tumor is in the sacrococcygeal area, there may be a problem with urination, and constipation and leg weakness may occur. A tumor in the chest may cause coughing, trouble breathing, or chest pain. A tumor in the brain may cause changes in eyesight or speech, weakness, extreme thirst, loss of appetite, growth problems, or early signs of puberty, such as breast development in young girls, voice deepening in young boys, or armpit or pubic hair growth in any young child.



■ WHAT CAUSES GERM CELL TUMORS?

There is no answer at this time as to the cause of germ cell tumors. It is important to understand that germ cell tumors are not contagious or "catchy," and they have nothing to do with germs that cause infections. Germ cell tumors are not caused by anything anyone did, including during pregnancy with the child. It is also important to understand that germ cell tumors are not caused by anything the child ate or did not eat (such as vegetables or vitamins).

■ WHO GETS GERM CELL TUMORS?

Germ cell tumors are a relatively rare type of tumor in childhood. Close to half of childhood germ cell tumors are cancerous. Only 2–3 out of every 1 million children will be diagnosed with a germ cell tumor each year. Germ cell tumors are most likely to occur in very young children (infants and toddlers) and in

teens, but they can occur in children of any age. Boys with an undescended testicle (even if it has been surgically fixed) are at an increased risk of developing a germ cell tumor of the testicle.

■ ARE GERM CELL TUMORS INHERITED?

It does not appear that germ cell tumors are genetic (inherited from a parent). It is very rare to have more than one person in a family with a germ cell tumor.

■ WHAT ARE METASTASES?

Metastases refer to the spread of the tumor from its first spot to other parts of the body. If germ cell tumors metastasize, or spread, the most common places are to the lungs, liver, and central nervous system (brain).

■ WHAT IS STAGING?

Staging is a way of identifying the location and amount of tumor at the time of diagnosis. There are four stages of germ cell tumors.

- Stage I** The tumor can be fully removed surgically, the tumor has not spread, and the tumor markers are normal.
- Stage II and III** The tumor has spread to area tissues or lymph nodes and may not be removed fully with surgery alone.
- Stage IV** The tumor has spread to at least one other part of the body.



The treatment method suggested for your child depends upon the stage of disease at the time of diagnosis.

■ WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

In order to diagnose a germ cell tumor and decide the extent of your child's disease, a number of tests and procedures will be needed, including many of these:

TUMOR BIOPSY

A tissue biopsy is the removal of a small amount of tissue to look at under a microscope. This test is needed to confirm the diagnosis and decide what the best treatment is. The biopsy is most often done in the operating room by a surgeon while the child is asleep under anesthesia. A piece of your child's tumor is then removed and sent to the lab. A pathologist—a doctor who is an expert at recognizing different types of cells—studies the tissue and then confirms the type of germ cell tumor the child has.

BLOOD TESTS

Blood tests are done to watch your child's blood cells, body salts, and chemistries. A complete blood count (CBC) detects changes in your child's white blood cells (infection fighters), red blood cells (cells that

carry oxygen), and platelets (cells that help blood clot properly). Tests of body salts and chemistries show how well your child's kidneys and liver are working. Other blood tests look for tumor cell "markers," which are proteins produced by tumors that can be measured in the blood. The two proteins that can be used as markers are alpha-fetoprotein (AFP) and beta human chorionic gonadotropin (β hCG). These blood tests will be used to track your child throughout treatment.

MRI

Magnetic resonance imaging (MRI) is a test that gives exact pictures of the inside of the body. Your child will be asked to lie on a table that will move into a tube-like machine, surrounding him or her with a magnetic field. Your child will be asked to wear clothing without metal, because this can cause an incorrect picture. Sometimes, to get the best MRI, a special dye (contrast) needs to be given into a vein before the test. The dye helps the doctor see parts of the body more clearly.

The machine can be loud, and your child will be instructed not to move at all during the test. Children who are not able to lie completely still may be given medicine (sedation) to help them sleep during this test. The person who runs the MRI machine will be in another room watching, and the test can take 1 hour or longer to finish.

CAT SCAN

The computerized axial tomography (CAT) scan is a painless computer-assisted X-ray that shows exact pictures of internal organs and tumors. Your child must be able to lie totally still during the scan. Younger children may need to be sedated to lie still and drink a flavorless dye that will help make the pictures clearer before the CAT scan. In other cases, a small amount of dye may be injected into a vein. Usually, there are no side effects from either type of dye; however, allergic reactions to the dye do occur in a small number of children.

BONE SCAN

A bone scan is done to find out whether the germ cell tumor has spread (metastasized) to any of the bones. A small amount of isotope (radioactive marker that makes any areas of tumor in the bone light up in pictures) is injected into a vein. About 2–3 hours later, pictures are taken of the child's whole body. The scanning is painless, but young children may need sedation to help them lie still during this test.

CHEST X-RAY

A chest X-ray may be needed to find out if the tumor has spread to the lungs.

ULTRASOUND

This test uses high-frequency sound waves to look at internal body organs or tumors. It can help spot tumors in the lymph nodes, abdomen, and scrotum. It is painless and involves no radiation. If the abdomen is being looked at, your child cannot eat or drink anything for about 4 hours before the test, but can restart eating a normal diet after the test.

VENOUS ACCESS DEVICE (VAD)

A VAD (central line) is a permanent intravenous (IV) tube that can be used during your child's treatment. It can be used for blood tests and can give medicines (including chemotherapy), red blood cells or platelets, and nutritional support if needed. It is put in when your child is under heavy sedation or anesthesia. Together, you and your child's doctor will decide if your child needs a VAD during treatment.

■ HOW CAN GERM CELL TUMORS BE TREATED?

Three types of therapy are most often used to treat germ cell tumors: surgery, chemotherapy, and radiation. The type of treatment offered to your child will depend upon the type of tumor and the amount of disease. A combination of treatments is often used. Your child's doctor will talk with you about the best treatment choices for your child.

SURGERY

The main treatment for benign and malignant germ cell tumors is surgery. Surgery to remove the main part of the tumor is most often done at the time of diagnosis. This is when the biopsy may be taken. For some noncancerous germ cell tumors, surgery may be the only treatment needed. For very large cancerous tumors, chemotherapy or radiation may be given first to shrink the tumor before surgery. A "second-look" surgery may be done after your child has received a certain amount of treatment. This type of surgery is done to observe your child's response to the treatment and to plan for any further therapy that may be needed.

CHEMOTHERAPY

Chemotherapy is the use of medicines to stop cancer cell growth. Some chemotherapy drugs are known to be useful in the treatment of germ cell tumors, but there is no single chemotherapy medicine that can control this disease by itself. Each of the medicines kills the cancer cells in a different way, and this is why two or more chemotherapy medicines are often given together. Most chemotherapy medicines are given through a vein, and each treatment can last several days. When chemotherapy is needed, close monitoring of your child will be a priority. Your child's healthcare provider will talk to you about the possible side effects of the specific chemotherapy treatment advised for your child, as well as the medicines that can be given to control the chemotherapy side effects.

RADIATION

Radiation therapy may be used in the treatment of some germ cell tumors. If radiation is needed for your child, the radiation oncologist will discuss with you how the radiation will be given and how long the treatments will last. Most of the time, children experience only a few side effects, such as tiredness or a decreased appetite, while they are getting radiation therapy. The possible side effects will be discussed with you in detail. Radiation treatment is very precise and is given in specially measured amounts by radiation therapy experts.



■ HOW LONG WILL MY CHILD'S THERAPY LAST?

This depends on the type and stage of your child's tumor at the time of diagnosis. Most often, the treatment is given over several months. Follow-up blood tests and checkups between and after treatments are often done in the clinic or doctor's office.

■ WHAT NEW METHODS OF TREATMENT ARE THERE?

Clinical trials and research studies have provided progress and scientific discoveries to (continually) advance the treatment of childhood cancer. A clinical trial compares the best known (standard) treatment for a certain cancer with a new (experimental) treatment that is believed to be at least as good as, and possibly better than, the standard treatment. Clinical trials let doctors decide whether promising new treatments are safe and effective.

Joining in clinical trials is voluntary and requires informed consent. During the informed consent, the treatment choices and how they differ are explained. Because clinical trials involve research into new treatment plans, all risks cannot be known beforehand, and unknown side effects may occur. Before making a decision about your child's participation in a clinical trial, you should talk about the risks as well as the potential benefits with your child's doctor and treatment team.

More information about clinical trials is available from the National Cancer Institute in the free booklet *Taking Part in Cancer Treatment Research Studies*. To get the booklet as well other information about childhood cancer, dial 800.4.CANCER (800.422.6237) or visit the National Cancer Institute Web page at www.cancer.gov.

■ HOW CAN I WORK WITH THE HEALTHCARE TEAM?

Your child's care requires a team approach. As a parent, you are a major part of the team—your input is important.

It is important to talk openly with your child's healthcare team. Be sure to ask questions about anything you are not sure of. It helps to write down your questions when you think of them.

Here are some examples of questions to ask:

- What kind of cancer does my child have?
- Has the cancer spread past the first site?
- What is the stage of the cancer, and what does that mean?
- What treatment choices are possible?
- What treatment do you suggest, and why?
- What risks or side effects does the suggested treatment have?
- What should we do to get ready for treatment?
- What is my child's outlook for survival?
- What are the chances of a recurrence?



Use this space to write down some of the additional questions you might have:

■ ARE MY FEELINGS NORMAL AND WHAT CAN I DO ABOUT THEM?

Hearing that your child has cancer can be shocking and overwhelming. At first, you may not believe it, or you may hope that the diagnosis is wrong. However, eventually, the changes you see in your child, the hospital experience, and the start of treatment will no doubt confirm the reality of your child's situation.

Many family members feel that they are somehow responsible for their child's disease, or they feel guilty that they were not able to find it sooner. Remember that this disease often does not become noticeable until it is in the later stages, so there may have been no way of seeing it in the early stages.

Besides possibly feeling shock and guilt, you and your family will probably feel anger and sadness. Even the youngest family members, such as brothers and sisters, are likely to be affected. These feelings are normal, and each family member will express them in different ways and at different times. It can be difficult to feel so many strong emotions all at once. Talking honestly with each other about feelings, reactions, and questions will help everyone in the family. It may seem hard to talk to friends, family, or even medical staff, but talking about your feelings will help you cope. Your child will benefit if loved ones continue to show their care through support and communication. The team will include professional to help with these reactions.

■ HOW CAN I HELP MY CHILD?

As a parent, you will often notice some changes in your child during treatment. These changes or symptoms may cause you to feel discouraged, worried, or nervous. The changes can be due to both the disease and the treatment. It is important to remember that, while there may be changes on the outside, your child is still the same person on the inside. Changes in body appearance, such as hair loss, are temporary. All of your feelings about what your child is going through during treatment should be balanced by remembering that treatment gives a chance to cure the disease and the opportunity for your child to go on to live a full and meaningful life.

It is vital to stress to your child and his or her brothers and sisters that nothing he or she did or said caused this disease. Sometimes, telling your child that your anger or sad feelings are directed at the tumor and not at him or her will help keep your special bond honest and close. Like you, your child will need someone with whom he or she can trust to share feelings. It can be helpful to ask your child what his or her feelings are. Despite your child's disease, he or she is still growing and learning. All children need love, attention, discipline, limits, and the chance to try new skills and activities. As you start to learn the new, special needs of your child, it is important to remember that he or she still has all the needs and rights of any growing, developing person. Use age-appropriate terms and explanations with your child. Children will handle treatment better if they understand it and are allowed to be active decision-makers when possible—the same is true for parents!



■ IS MY CHILD'S DIET IMPORTANT DURING THE TREATMENT?

We know from research that well-nourished children handle therapy better and have less treatment delays due to sickness. It may be hard for your child to resume normal eating habits while on therapy, so you will need to be flexible and creative. Your child may not be able to eat three large meals every day, so encouraging small meals more often may make it easier for your child to get enough nutrition during treatment. Make foods high in calories and protein available as often as possible. Children will be more interested in eating foods that they help make. It is important to involve your child in the social activity of family meals even if your child is not able to finish the meal. Your child's healthcare provider should know about, and approve, all medicines, including vitamins and other supplements. A registered dietitian can offer you guidance in helping to get the best nutrition for your child. If eating and getting enough nutrition is a struggle, the medical staff can help. Nobody wins food fights—it is best not to force your child to eat, but rather, to offer support and encouragement.



■ CAN MY CHILD GO TO SCHOOL DURING TREATMENT?

Your child's ability and desire to go to school will depend on the intensity of the therapy and the response to treatment. Your child may not be able to go to school for long periods due to treatment or a hospital stay. However, it is vital that your child keeps up with his or her schoolwork as best as they are able to. Working with the school to set up appropriate goals is key to your child's success during this time. Work with your child's school about setting up these goals and providing services that can include a home tutor until your child is able to return to school. It is



important to speak to your child's healthcare providers for support and to help teach the school about your child. Some pediatric hospitals allow children to go to school while hospitalized. A home tutor can also be arranged if your child is not able to go to his or her normal school. But it is important to know that schoolwork may need to be reduced to only cover the basic core that is needed so that your child can be successful.

School is important because it helps children keep up social contact with their peers. Spending time with friends will be an important part of your child's healing and will ease the adjustment when he or she returns to school. Even if your child can go to only a few classes, this can help ease feelings of isolation and loneliness. It is important for your child to return to school as soon as he or she is medically able to do so.

Brothers and sisters who go to school will also benefit from support. Communicating with the school about changes at home, and alerting teachers to watch for changes in the brothers' and sisters' coping, learning, and peer relationships, is very important. Brothers and sisters often value having a break from the attention and worries that are focused on their sick brother or sister while they are in school.

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IN RECOGNITION OF PREVIOUS CONTRIBUTORS

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