APSA
American Pediatric Surgical Association
Saving Lifetimes

Sacrococcygeal Teratoma

Patient and family information, brought to you by the Education Committee of APSA

Overview - "What is it?"

Sacrococcygeal teratoma (SCT) is a type of tumor that starts at the end of the tailbone (coccyx). It can be quite large and extend outside of the body and/or inside the belly. The tumor contains many different types of tissue including hair, teeth, bone, muscle, nerve, among others. There can be cancer tissue within SCT, however, the likelihood of cancer is higher in older children, and much less in newborns.

Most SCT in newborns are non-cancerous.

SCTs are the most common tumor seen in newborn infants, occurring in 1 in 30,000-70,000 live births. SCTs are more common in girls. Most SCTs are found in infants, but some can be seen in toddlers and children four years or younger. Larger tumors, especially those outside the body, are often seen on prenatal ultrasound. Twelve to fifteen percent of children with SCTs have associated congenital anomalies, most commonly anorectal malformations, and spinal abnormalities.

Signs and Symptoms - "What symptoms will my child have?"

Early symptoms: Mass is seen starting from the tailbone. In some cases, the tumor may be mostly within the belly and is difficult to diagnose on the outside.

Tumor complications:

- If the mass is very large, the heart has to pump large amounts of blood to the tumor. Symptoms of heart failure that can be seen even while the baby is still in the uterus include fluid around the lungs, in the belly, around the heart and within the baby's tissues. This condition is called "hydrops fetalis".
- Bleeding from mass
- Tumor rupture: When the skin from the tumor rips off
- If a large part of tumor is inside the belly, it can block the flow of urine or stool.

Diagnosis - "What tests are done to find out what my child has?"

Labs and tests

Blood tests: AFP, beta-HCG levels. These proteins are made by the tumor. Other blood tests such as blood count and electrolytes (minerals) will also be checked.

Computed tomography (CT) or Magnetic Resonance Imaging (MRI) of the abdomen/pelvis will look at how big the mass is, the extent of the tumor located and blood supply.

Chest X-ray or CT to look for pulmonary spread.

Conditions that mimic this condition: Lipomeningocele, lipoma, chordoma (spinal cord anomalies), Rectal duplication, Epidermoid cyst, Neuroblastoma (tumor from neural crest cells).

Treatment - "What will be done to make my child better?"

Prenatal Care: Since SCTs can have complications, the mother of the baby undergoes frequent visits to her obstetrician for check-ups and ultrasounds to monitor for signs of heart failure and/or hydrops.

In most cases of SCT that is external to the baby, a Caesarian section (C-section) is recommended to avoid bleeding or rupture of the tumor.

Medicine: There is no medicine to treat the mass, only surgery

Surgery:

Preoperative preparation: Intravenous antibiotics to help prevent infection.

Procedure: The goal of the surgery is to completely remove the mass. Depending on the location, the cuts (incisions) needed for the surgery can be by the buttocks only (external masses), the belly only (internal masses) or both. The tailbone (coccyx) is removed with the tumor. Not removing the coccyx is associated with up to 40% recurrence of the tumor. Sometimes a small plastic drain is placed under the skin flaps of the buttock incision.

The mass will be sent for examination to see if there are components of cancer in the mass. If cancer is seen in the mass, the baby will need medicine (chemotherapy) to help control the recurrence of cancer. If this is the case, cancer specialists (oncologists) will be involved in the care of your baby.

Postoperative care:

- Baby often has to lay on belly for first couple of days after surgery to let the incision heal
- Incisions may open up and need dressing changes
- Drain is usually left in place for 3-7 days after surgery

- Medications needed will include pain medications, antibiotics and maybe nutrition delivered through the vein

Risks of surgery:

- Bleeding requiring transfusion
- Wound breakdown—the skin close to the tumor can have a fragile blood supply
- Wound infection
- Urinary retention—there is a high risk of urinary problems after this procedure, likely due to the stretch of the nerves and muscles of the pelvis. The length of time that this is a problem varies from one child to another.
- Incontinence of muscles of anus—there is a risk of having problem with continence of stool. Often the tumor stretches the muscles involved in control of continence. This will gradually get better in most cases.

Benefits of surgery: Removal of mass

Informed consent: A consent form is a legal document that states the tests, treatments or procedures that your child may need and the doctor or practitioner that will perform them. Before surgery, your doctor should tell you what the operation is, the goal of the surgery and other possible treatment options that are available. Your doctor should explain the risks and benefits of the surgery. You give your permission when you sign the consent form. You can have someone sign this form for you if you are not able to sign it. You have the right to understand your child's medical care in words you know. Before you sign the consent form, make sure all your questions are answered. It is important to know that during surgery, there are things that can happen that your doctor may have not predicted before going in. He or she will explain these to you after the surgery.

Home Care - "What do I need to do once my child goes home?"

Diet: Normal for age.

Activity: Normal for age.

Wound care: Depends on wound. May need to do dressing changes if wound has opened up. In this case, your surgeon will help explain wound management, as it differs from one child to another.

Medicines: Pain medications such as acetaminophen (Tylenol®) may be needed.

What to call the doctor for: Redness, warmth, or drainage from incision. Problems with urinating or stooling.

Follow-up care: Regular follow-up with surgeon for physical examinations and checking AFP levels in the blood, just as was done before surgery. Since AFP is made by the tumor, blood levels should normalize once the tumor is removed. AFP levels are tracked regularly because if it increases, it signals tumor recurrence.

If cancer is present in the mass or if there are metastases (tumor spread beyond the main tumor such as the lungs, for example), the child will need follow-up with oncology for chemotherapy.

Long Term Outcomes - "Are there future conditions to worry about?"

Survival rate for sacrococcygeal teratomas is more than 95%. The risk of bowel or bladder dysfunction even in benign tumors is quoted as 30-40%. Tumor recurrence can happen, therefore careful follow up is needed.

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