Sacrococcygeal Teratoma (SCT)

Patient Information Series – What you should know, what you should ask.

What is a Sacrococcygeal Teratoma (SCT)?

A sacrococcygeal teratoma (SCT) is a rare tumor that develops in the lower back near the tailbone (the coccyx or presacral area). It occurs in about 1 in 10,000 to 1 in 40,000 live births and is more common in females (4:1 female-to-male ratio).

The tumor can be mostly external (outside the body) or internal (inside the pelvis). Although these tumors can grow quite large, they are rarely cancerous (malignant).

SCT is usually detected during pregnancy by ultrasound or may be suspected due to abnormal levels of alpha-fetoprotein (AFP) in the mother's blood. Further imaging helps rule out spinal abnormalities.

How does an SCT happen?

SCTs are thought to arise from totipotent cells (early embryo cells that can become any cell type) in a region called Hensen's node during early development.

These tumors can be:

- Benign (non-cancerous): Often cystic and slow-growing.
- Immature teratomas: Contain embryonic tissue and may behave unpredictably.
- Malignant: Usually solid, fast-growing, and highly vascular (rich in blood vessels).

Rarely, SCTs are associated with other malformations, except in cases where the tumor causes hydrops (fluid buildup in the fetus) or polyhydramnios (excess amniotic fluid) due to high cardiac output.

Chromosomal or genetic anomalies are uncommon.

Should I have more tests done?

Additional tests may be recommended, depending on your location and available resources. You may want to ask about:

- Amniocentesis or chorionic villus sampling (CVS): To check for chromosomal abnormalities, though these are rarely associated with SCT. Genetic counseling and genetic testing may include tests to check for chromosomal abnormalities and other genetic diagnostic tests such as chromosomal microarray testing or whole exome sequencing. Such testing can provide essential information regarding your individual case.
- Fetal echocardiography: Especially if hydrops is suspected, to assess the baby's heart.
- MRI: If available, this can give detailed images of the tumor and surrounding structures.
- Regular ultrasound with Doppler: To monitor the baby's condition and detect signs of fetal anemia.

What are the things to watch for during pregnancy?

Babies with SCT may face challenges during pregnancy. These include:

- Hydrops and heart failure: Due to the extra work the fetal heart must do to supply blood to the tumor.
- Fetal anemia or low platelets (thrombocytopenia): Caused by blood cell destruction as blood passes through the tumor.

- Polyhydramnios: Too much fluid around the baby, often a result of heart stress.
- Hydronephrosis: Swelling of the kidneys from pressure on pelvic organs.

Frequent ultrasounds, including Doppler studies of the middle cerebral artery, help monitor these issues.

What does it mean for my baby after birth?

The outcome depends on:

1. Presence of hydrops – linked to higher risk of death due to heart failure.
2. Tumor type – benign tumors have a better prognosis; malignant ones are often fatal and hard to remove.
3. Tumor size and location – large tumors or those with many blood vessels carry more surgical risk.

If the tumor is mostly external, cystic, and not highly vascular, surgery is often successful. Babies may need specialized care and multiple surgeries in a neonatal intensive care unit (NICU) after birth.
If genetic abnormalities are found, additional complications may occur, and outcomes vary depending on the specific condition.

Will it happen again?

If no underlying genetic cause is found, the chance of SCT happening again in a future pregnancy is extremely low.

What other questions should I ask?

- Does this look like a malignant SCT?
- How large is the mass? Is it mostly internal or external?
- Should I have an MRI?
- Are there signs of hydrops or heart problems?
- Can the pregnancy be terminated?
- How often will I need ultrasounds?
- Is fetal surgery an option?
- Where and how should I deliver?
- Where will my baby receive care after birth?
- Can I meet the neonatal and surgical team in advance?

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