Sickle Beta Zero Thalassemia

Sickle beta zero thalassemia (sickle β⁰ thalassemia) is a type of sickle cell disease that is similar to sickle cell anemia. People with sickle β⁰ thalassemia have one sickle hemoglobin gene and one beta thalassemia gene. These genes were passed on to a child from the parents. Your child was born with this disease. It can not be spread to other people. Sickle β⁰ thalassemia can only be passed to a child through the parent’s genes.

Things to expect:

- Your child will always be anemic (low hemoglobin). This may make him more tired than others at times, especially during physical activities. Taking iron medication will not fix the low hemoglobin.
- Your child may be at higher risk of getting a serious infection. These infections include meningitis (infection of the lining of the spinal canal), pneumonia (infection of the lungs), blood infections or bone infections.
- Painful episodes may commonly happen in this type of sickle cell disease. Some children have many painful episodes during their life but others with this type of sickle cell do not have much pain. Your sickle cell nurse or doctor will teach you ways to prevent pain and give you medicines to help your child with the pain, if needed.

Things to do to prevent problems:

- Have your child rest when he feels tired.
- Have your child drink extra water and fluids.
- Avoid very hot or cold temperatures when possible.
- Give your child all the medicines ordered by your doctor. Penicillin twice a day every day is very important when children are young to help prevent infections.
- Your child should get all of his regular immunizations from the primary care provider. Extra immunizations may be given by the sickle cell team to help give additional protection against infection.
- Have your child’s eyes checked by an eye doctor (ophthalmologist) every year starting at age 7 years.
- Your child should have a sickle cell clinic appointment once a year or more often if needed.

Call the sickle cell nurse or doctor at (816) 234-3265 (Monday through Friday, 8 am to 5 pm) or the Hematology/Oncology nurse on call at (816) 234-3000 (after office hours, and on weekends and holidays) if your child:

- Has a fever of 101.5°F (38.6°C) or higher.
- Looks pale.
- Seems more tired than usual.
- Has pain that will not go away with medicine.