Sickle Hereditary Persistence of Fetal Hemoglobin

Sickle hereditary persistence of fetal hemoglobin (S/HPFH) is a less common type of sickle cell disease. People with S/HPFH have one sickle hemoglobin gene and one hereditary persistence of fetal hemoglobin gene. These genes were passed on to the child from the parents. Your child was born with this type of sickle cell disease. It can not be spread to other people. S/HPFH can only be passed to a child through a parent’s gene.

Things to expect:

- Your child may have mild anemia (low blood) but not enough to cause any problems. This may sometimes make him more tired than others, especially during physical activities. Taking iron medication will not fix the low hemoglobin.
- People with this type of sickle cell disease usually do not have problems with painful episodes but pain could happen at times.
- 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 in the lungs), blood infections or bone infections.

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 his doctor.
- Your child should get all of his regular immunizations from his primary care providers. 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.