What you can do

As this child's primary caretaker, there are some things you can do to help your child stay healthy.

Make sure that your child attends all regularly scheduled doctor appointments, both with your pediatrician and with your sickle cell doctors.

Encourage your child to eat regular, healthy meals, drink plenty of fluids and get enough rest at night.

In addition, if your child develops problems or you have questions about your child's condition at any time, please seek the advice of a physician.

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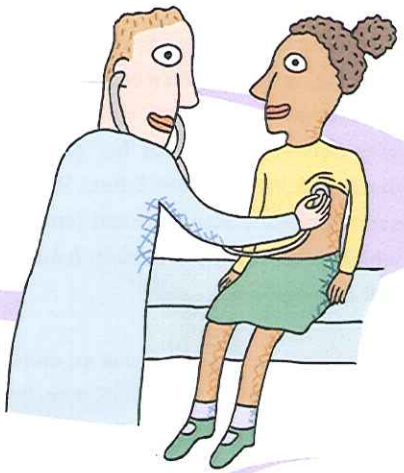
HEMOGLOBIN S BETA PLUS THALASSEMIA

A guide for parents



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What is Hemoglobin S Beta Plus Thalassemia?

Hemoglobin S Beta Plus Thalassemia is the mildest form of sickle cell disease. Your child has inherited the sickle cell gene from one parent and the Thalassemia gene from the other parent. This combination of genes produces this disease.

Hemoglobin S Beta Plus Thalassemia is a lifelong disorder. Your child will always have this disease, but there are some things you can do to help them stay healthy.

On a scale of 1 to 10, patients who have this disease will likely have a low level of severity, probably between 3 and 6. You should not expect your child to have a lot of problems from his or her disease. Children with Hemoglobin S Beta Plus Thalassemia produce some normal hemoglobin, which gives them protection from sickle cell hemoglobin.

There are some similarities to children who have sickle cell anemia, also known as Hemoglobin SS Disease These include risk of infection, mild anemia, and mild discomfort. Your sickle cell doctors will help you understand these problems in detail.

Special Problems for Children with Hemoglobin S Beta Plus Thalassemia

All children who have any form of sickle cell disease are at risk for infection. Because the spleen does not work very well, if your child gets one type of infection, called a "Pneumococcal" infection, he or she may get very sick very quickly. The best way to prevent problems from this infection is to make sure your child receives Penicillin daily, gets all immunizations and sees his or her doctor for a fever greater than 101 degrees.

Most children who have this disorder do not experience a lot of discomfort. Sometimes, though, your child may complain of pain. If this does occur, you should make sure they drink plenty of fluids and give them the pain medication recommended by their doctor.

Sometimes they may be tired or pale in color. This occurs if the body's blood count gets lower than normal. Allow for plenty of rest and call their physician if these symptoms do not improve.

What should you expect

Children with Hemoglobin S Beta Plus Thalassemia have the **mildest** form of sickle cell disorders. They are very likely to experience very few problems from this condition. You should expect them to lead a normal lifestyle and have a relatively normal life span.

Children with this condition should attend school regularly and participate in physical education activities. Organized team sports participation should be cleared by your sickle cell doctor prior to enrolling. They should grow and develop into a relatively healthy young adult and should not be encouraged to think of themselves as "sick".

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