Referring to a sickle cell program

By Clarissa Johnson, M.D.

Hematology and Oncology Center

For non-emergent referrals and consults contact:
Hematology and Oncology Center
682-885-4007

When to refer

Infants with confirmed sickle cell disease – with positive FS, FSC and FSA – should be referred to a pediatric hematologist that provides treatment in an established sickle cell center.

Cook children's expert hematologists provide a specialized, comprehensive sickle cell clinic, which includes:

- Ongoing patient and family education
- Periodic comprehensive evaluations: transcranial doppler screening (TCD) to assess risk for stroke which is standard of care for children with severe disease types, echocardiogram (ECHO), electrocardiogram (EKG), lab evaluations, routine eye exams and screening for sickle nephropathy
- Other disease-specific health maintenance services
- Timely and appropriate treatment of acute illnesses
- Genetic counseling
- Psychosocial support
- A transition program

Testing and diagnostic procedures

- All newborns in the United States are screened for sickle cell disease, so most children are diagnosed early in life.
- Genetic testing and specific types of blood tests enable specialists to determine the type of sickle cell disease the patient has in order to determine the best course of short- and long-term treatment.

Syndrome	Neonatal screening
Sickle cell anemia (HbSS)	FS
Sickle cell beta zero thalassemia (Hb SßThal-O)	FS
Sickle-hemoglobin C disease (Hb SC)	FSC
Sickle beta plus ($Sß^{+}$) thalassemia	FSA or FS[3]

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One of the greatest advances in the management of sickle cell disease is stem cell transplantation.
A stem cell transplant replaces unhealthy red blood cells with red blood cells from a healthy donor and, in most cases, can restore a patient to a sickle cell disease-free life. A patient's eligibility for stem cell transplant requires a donor match. The people most likely to provide a match are full siblings. It is also sometimes possible to find a match from outside the family.

Who gets sickle cell disease?

Sickle cell disease is a genetic blood disorder, meaning it is passed down from parent to child. The sickle cell gene is most common among people whose ancestry is:

- African
- Arabian
- Asian Indian
- Mediterranean
- Hispanic from the Caribbean and Central and South America

Symptoms and complications

Depending on the type of sickle cell disease, the patient may not have any symptoms, and symptoms can range from mild to severe. Some of the most common are:

- Jaundice
- Anemia
- Pain
- Gallbladder disease
- Damage to the kidneys, lungs and other vital organs
- Infection
- Acute chest syndrome
- Enlarged spleen
- Aplastic crisis
- Stroke
- Priapism
- Delayed growth

Treatment

Cook Children's provides treatments and therapies to help control sickle cell disease and alleviate complications based on guidelines from the National Heart, Lung and Blood Institute.*

Treatments include:

- Pain management
- Antibiotics and penicillin prophylaxis
- Immunizations – all recommended vaccines, pneumococcal 23-valent, meningococcal and annual influenza
- Blood transfusions/red blood cell exchange transfusion
- Hydroxyurea
- Stem cell transplantation, including gene therapy
- Surgery

*nhlbi.nih.gov/health-pro/guidelines/sickle-cell-disease-guidelines

The Cook Children's sickle cell program serves more than 600 children from across Texas and adjoining states annually. Our program offers testing, diagnosis and treatment for the many types of sickle cell disease.

Cook Direct Connect

682-885-1940

To better serve our treating clinicians we can assist you with:

- Non-emergent transfer requests
- Direct admissions
- Specialist consultations

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