



Sickle Cell Disease & Children

MANAGING SICKLE CELL TO REDUCE FUTURE RISKS

By La Rabida Children's Hospital – The Chronic Illness Experts | www.larabida.org

Chronic But Manageable

Sickle cell disease is a genetic disorder affecting the red blood cells. In the United States, an estimated 70,000 people live with sickle cell disease, with about 1,000 babies born with the disease each year.

A simple blood test helps diagnose the disorder of which there are several types: Sickle Cell Anemia (SS), Sickle-Hemoglobin C Disease (SC), Sickle Beta-Plus Thalassemia and Sickle Beta-Zero Thalassemia. Sickle cell disease is a lifelong condition and there is no universal cure; a bone marrow transplant is a successful cure in some cases. Proper medical attention and management of the disease can help reduce risks and complications associated with the disease.

People with sickle cell disease have red blood cells that contain mostly hemoglobin S, an abnormal type of hemoglobin. Sometimes these red blood cells become sickle-shaped (crescent shaped) and have difficulty passing through small blood vessels. When sickle-shaped cells block small blood vessels, less oxygen can reach that part of the body.

COMPLICATIONS AND TREATMENT

Tissue that does not receive a normal blood flow eventually becomes damaged. Inadequate oxygen may cause complications of the disease: lung tissue damage (acute chest syndrome), pain episodes (arms, legs, chest and abdomen), stroke and priapism (painful prolonged erection) and damage to major organs – kidneys, liver and spleen.

Damage to the spleen makes sickle cell disease patients, especially young children, easily overwhelmed by certain bacterial infections.

Sickle cell screening at birth is required by the State of Illinois. Disease management education begins upon diagnosis. Treatment usually begins with penicillin prophylaxis when the child is 2 months old. Vaccination against pneumococcus bacteria and folic acid supplementation. Treatment of complications often includes antibiotics, intravenous fluids and blood transfusion, all backed by psychosocial support. Children with sickle cell disease are best managed in a comprehensive interdisciplinary program of care.

MANAGING YOUR CHILD'S CARE

Managing a child's sickle cell disease can affect the whole family. Acute pain is a symptom of this chronic illness and often requires immediate medical attention and possibly blood transfusions. Because of the heightened risk for bacterial infections, children's exposure to infection risks needs to be monitored.

Parents are the first line of defense for children with sickle cell disease. As the child grows older and more self-reliant, one can successfully manage his or her own health. Parental and self-management, however, requires ongoing education.

Teaming with pediatric sickle cell experts including physicians, nurse educators and psychologists will help ensure the child with sickle cell disease and their parents have the knowledge they need to well manage the medical condition.

CHOOSE A PEDIATRIC SICKLE CELL EXPERT

When it comes to treating children with sickle cell disease, there is no substitute for medical professionals who are trained in pediatric medicine and are sickle cell experts. Understanding the body, mind and spirit of the child is essential to the successful management of sickle cell disease.

SICKLE CELL TREATMENT AT LA RABIDA CHILDREN'S HOSPITAL

La Rabida's sickle cell team works closely with the State of Illinois Newborn Screening Program and is one of the state's main referral centers for babies diagnosed with sickle cell disease.

An interdisciplinary team led by a pediatric board-certified hematologist includes a nurse specialist, child psychologist and licensed social workers who work together to create a custom treatment plan for each child.

La Rabida provides inpatient and out-patient treatment for children with sickle cell disease, including urgent treatment.

Education and counseling for children with sickle cell and their families is central to La Rabida's overall approach.

Public and most private insurance is accepted.

To make an appointment, call: **773.753.8626**.



La Rabida Children's Hospital



A specialty hospital for children with chronic illness and developmental disabilities.

About La Rabida

La Rabida is a resource upon which Chicago's families have depended since 1896. Our mission to provide care to children with lifelong medical conditions regardless of their family's ability to pay has been unwavering.

Today, La Rabida serves approximately 9,000 children annually who require primary and specialty care to address complex and challenging medical conditions. Services and programs include treatment for chronic illnesses such as asthma, diabetes, and sickle cell disease, and developmental disabilities. In addition, La Rabida specializes in the treatment of children who have been abused, neglected or experienced trauma.

Under one roof, La Rabida offers access to board-certified pediatricians and specialty physicians, behavioral science professionals, advance practice nurses, physical and occupational therapists, speech pathologists, dietitians, case managers and social workers. All have dedicated their careers to pediatric health care and are committed to our philosophy of care.

La Rabida is a recognized leader in its treatment of chronic disease, disabilities, abuse and trauma and works closely with leading institutions who refer patients for specialty care. It attracts high caliber health care professionals for the many career and training opportunities it offers. It is affiliated with Children's Memorial Hospital and the University of Chicago.

We are blessed with a magnificent Lakeside location just minutes from the heart of downtown Chicago. Our facility is designed to show off its spectacular views and inspire hope for every child and family who crosses our threshold.

Visit www.larabida.org. You will come to understand why La Rabida is so special.

COORDINATES AND CONTACTS

La Rabida Children's Hospital is located on Lake Michigan, directly east of Jackson Harbor, a mile south of the Museum of Science and Industry. To Mapquest directions, input 6501 S. Promontory Drive, Chicago, IL 60649 as the address. General Inquires: 773.363.6700. To make an appointment with a sickle cell provider: 773.753.8626

Our Approach to Sickle Cell Disease Treatment

Medical management of sickle cell disease is one La Rabida's specialties. Sickle cell disease will affect the spleen and if left untreated can damage the lungs, liver and kidneys. There are different types of sickle cell disease, with commonly known types being sickle cell anemia, sickle-hemoglobin C disease and sickle thalassemia. Our goal is to minimize risks and maximize the child's potential for a rewarding future.

Children with sickle cell disease have special needs that require treatment and support from an interdisciplinary team. Upon diagnosis, a hematologist and nurse specialist create an individualized treatment plan for the sickle cell patient that includes disease management strategies, genetic counseling, parent and family education and, where needed, the services of a social worker, child psychologist, dietitians, physical therapist, occupational therapist and speech language pathologist.

Children receive comprehensive, family-oriented care on either an inpatient or outpatient basis.

CHECK-OUT OUR WEBSITE TO LEARN MORE ABOUT LA RABIDA'S SICKLE CELL PROGRAM. | WWW.LARABIDA.ORG