our program

The Comprehensive Sickle Cell and Thalassemia Program at Nationwide Children's Hospital is the only program in central Ohio offering dedicated services for children and young adults with sickle cell disease, thalassemia and other hemoglobin (red blood cell) disorders. Our multidisciplinary team provides comprehensive medical and psychosocial care for over 300 patients annually. We also provide confirmatory testing for children and education for families whose child is identified with an abnormal hemoglobin disorder through our newborn screening process.

As one of six centers funded by the Ohio Department of Health, we offer a full range of medical, educational, and supportive services throughout a 33 county region in central and southeastern Ohio. Our program services include inpatient and outpatient medical care, newborn screening, genetic counseling, social services, psychological testing, counseling and education.

our team

The Comprehensive Sickle Cell and Thalassemia Program at Nationwide Children's Hospital strives to provide the highest quality of care and education in a manner that respects the cultural diversity of the community that we serve. Members of our team include:

:: Medical Director
:: Program Coordinator
:: Nurse Clinicians and Practitioners
:: Medical Social Worker
:: Clinical Psychologist
:: Genetic Counselor
:: Clinical Research Coordinator
:: Newborn Screening Coordinator
:: Regional Health Educator
:: Medical Secretary

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NATIONWIDE CHILDREN'S HOSPITAL℠

CH567.07.09.500

Hematology/Oncology & BMT

Russell, Sickle Cell Patient

The Comprehensive Sickle Cell and Thalassemia Program

NATIONWIDE CHILDREN'S HOSPITAL℠

program services

CLINICAL AND MEDICAL SERVICES

Led by a board-certified pediatric hematologist/oncologist, our highly trained team of medical providers uses a comprehensive approach in addressing the needs of individuals with sickle cell disease and related hemoglobin disorders. The full range of medical services in our clinic, day hospital and inpatient units include:

- Regular complete medical exams
- Diagnostic testing
- Prevention and management of pain and serious illness
- Blood transfusion therapy/apheresis
- Bone marrow transplant
- Ongoing education and support to patients, families and the community

NEWBORN SCREENING

Every year approximately 30 babies in our 33 county service area are diagnosed with sickle cell disease and referred for treatment. Over 800 newborns in our region are also identified annually as having sickle cell trait (carrying one sickle cell gene) or a related abnormal hemoglobin trait. When the test results indicate a child has a hemoglobin (red blood cell) disorder, our newborn screener coordinates testing to confirm the diagnosis and provides counseling and education to the parents whose child has trait. Individuals who have trait may not become ill, but if both parents carry the trait, there is a 25 percent chance with each pregnancy that they will have a child with sickle cell disease. The newborn screener helps families understand how the disease is inherited, and stresses the need for both parents to know their "trait status" so they will know whether they are at risk of having a child with sickle cell disease.

GENETIC COUNSELING

A genetic counselor is able to help families understand whether they are at risk of having a child with hemoglobin disease. If they already have a child with sickle cell disease, our genetic counselor can explain how the disease was inherited and the risks of having future children with the disease. The counselor does this by gathering information about a family's medical history and coordinating genetic testing in order to gain a complete picture of risk factors. Advanced genetic testing is available when necessary, as well as ongoing education and support regarding family planning decisions.

MEDICAL SOCIAL SERVICES

Social workers provide a broad range of services to support the social, emotional, medical and financial needs of patients and families affected by sickle cell disease and related disorders. Because chronic illness affects all aspects of a child's life, our goal is to help families manage their child's disease by providing them with information and referrals to medical and community resources. Our social workers may provide services through:

- Emotional support in coping with a new diagnosis and planning for ongoing needs
- Education about sickle cell disease and available resources
- Support during times of illness or family crisis
- Assistance in applying for insurance benefits or financial aid
- Coordination of transportation for medical appointments or school
- Consultation and education for teachers at the child's school or daycare

PSYCHOLOGICAL SERVICES

Patients with sickle cell disease and related disorders often struggle with the stress of chronic illness and pain that affects them emotionally and psychologically. Our pediatric psychologist helps patients and their families learn ways to manage their symptoms in order to minimize negative impacts on the quality of their lives. A broad range of psychological services for patients and their families are provided on an inpatient and outpatient basis including:

- Counseling and education on ways to cope with symptoms of chronic illness
- Psychological and educational testing for children experiencing developmental, learning, emotional or behavioral problems
- School advocacy to ensure the child's needs are met within the school environment
- Coordination of alternative approaches to pain management such as massage therapy, biofeedback, hypnosis and meditation

EDUCATIONAL SERVICES

Our regional health educator conducts workshops and educational events about sickle cell disease and related hemoglobin disorders throughout the 33 county region funded by our state grant. Our key goals of providing education and outreach are to increase community awareness of sickle cell disorders and the need for individuals to be tested to see if they are carriers of an abnormal hemoglobin trait. Community educational activities include:

- Workshops for health care professionals
- Presentations to schools, churches, civic groups, etc.
- Health fairs and community awareness events
- In-services for employers
- Development and distribution of educational materials and available resources