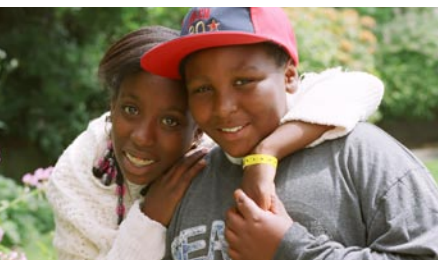


# A Lifeline in Rough Seas

The Odessa Brown Children's Clinic is improving the coordination of care for children with Sickle Cell Disease throughout our region.



**NICOLE SMITH WAS MET WITH RAISED EYEBROWS WHEN SHE CARRIED DAUGHTER ALEX, THEN 1, INTO THE EMERGENCY ROOM OF THE LOCAL HOSPITAL AND EXPLAINED THAT FEVERS CAN BE LIFE-THREATENING FOR CHILDREN WITH SICKLE CELL DISEASE (SCD).**

“Alex is probably the only child in Skagit County with SCD, and most doctors here haven't encountered it since medical school,” explains Smith. “So I handed the doctor the one phone number I keep with me at all times and told him to call Dr. Bender at Children's.”

For many families in Washington state, Dr. M.A. Bender, a pediatric hematology/oncology specialist at Children's, and the sickle cell team at the Odessa Brown Children's Clinic are a lifeline in rough seas. Most primary care and emergency room doctors have little experience managing SCD, an inherited disease in which irregular, “sickle-shaped” red blood cells are very stiff and can clog blood vessels, depriving the body's cells and tissues of blood and oxygen. Symptoms may include anemia, recurrent bacterial infections, clots in the lung, brain and spleen, and periodic pain crises.

SCD mainly affects black and Hispanic children, who face learning and health challenges at school, as well as ignorance about their condition in the community. Over the last 25 years, the team at Odessa Brown has worked to develop stronger partnerships with community providers and improve access to care that addresses the special needs of children with SCD.

## Improving outlook

Thirty years ago, 25 percent of sickle cell patients died before age 6. Thanks to dramatic improvements in managing the disease, most children with SCD today can expect to live into their 60s.

While early intervention with antibiotics and vitamin supplements is crucial for children born with SCD, the key factor in maintaining their good health is education. Health care providers must learn to recognize and treat the disease. Families must learn to manage the illness and help their children cope on a day-to-day basis. As the children grow, they need SCD specialists who will advocate for them and serve as resources for their other providers.

**ABOVE FROM TOP:** Ruth White, Sickle Cell Clinic's nurse practitioner. Cyclical health crises are a way of life for children with Sickle Cell Disease. (middle) Only 3, Phyllis has already been hospitalized many times in her young life. (bottom) Siblings Dominique, 13, and Ramon Cunningham, 11, are learning to be more involved in managing their health as they get older.



*Alex Smith, 2, travels from Skagit County to get the special care she needs from Dr. M.A. Bender at Odessa Brown Children's Clinic in Seattle's Central Area. "Alex's Sickle Cell Disease is very stable right now, but we're confident that when things aren't going so well, we know the best people to help," says dad Tony Smith.*

"I once called Odessa Brown in tears," recalls Flossie Cunningham, whose children, Dominique, 13, and Ramone, 11, both have SCD. "The teacher and principal wanted Dominique to repeat first grade because she missed so many days. I had explained that she would miss class because of her condition, but the school didn't get it. The Sickle Cell Clinic's nurse and social worker cleared their calendars and drove up to Lynnwood to meet with the school. They explained Dominique's condition and how the school could help her in the future. I never felt so supported. During the next school year, Dominique excelled because she got the attention she needed."

## Improving the model of care

In June, Children's received a three-year grant from the federal Department of Health and Human Services (DHHS) to support sickle cell patients, their families and communities through education and genetic counseling (which includes testing for sickle cell trait), improving access to specialty care and increasing services and education to community providers around the state — work that parallels what the sickle cell team at Odessa Brown is already doing and that we eventually hope to expand throughout Alaska, Montana and Idaho.

Children's is one of 18 organizations across the nation to receive this grant. Together, these community groups, hospitals and state programs will establish best practices for the care of children with SCD and those who carry sickle cell trait.

Odessa Brown will lead the effort in Washington to improve the statewide network of care so that all children with SCD will have access to the specialty services needed to manage the disease. Partners in this effort include Mary Bridge Children's Hospital in Tacoma, the Washington State Department of Health Newborn Screening Program, Sacred Heart Children's Hospital in Spokane, the Metropolitan Seattle Sickle Cell Task Force and Group Health Cooperative in Seattle.

Together, the partners will develop educational programs that give families the skills they need to better manage the illness. Common scenarios include: helping older teens take greater responsibility for their health so that their transition to an adult SCD center is easier; requesting a referral to a specialist when there is a hunch that something is not right; learning what to expect prior to an appointment or procedure so that the clinic or hospital experience is less intimidating; and knowing how to explain SCD to a school nurse.

Creating a computerized registry to track sickle cell patients in Washington is another aspect of the grant-funded project. The registry will allow the partners to keep tabs on children with SCD to make sure they receive the most appropriate treatment for their symptoms. In addition, the partners will monitor outcomes of the prescribed treatments for children around the state.

The grant will also enable Odessa Brown to host biannual meetings with providers across the state to discuss the latest methods of managing SCD, help community providers recognize possible symptoms of SCD and link providers with specialists for continuity of care. Within communities where a number of SCD patients and their families live, the partners will set up mentorship and networking programs to enrich support for patients and families.

"The Odessa Brown Sickle Cell Clinic is like that light when the tunnel narrows and gets dark. They keep me positive and psychologically up. I couldn't fathom our lives without them," says Cunningham.

**END**