

Tragedy to Awareness

continued **▲** from Front

be pinpointed to one crucial component; a lack of diagnoses.

Pastor Taylor found out her newborn, Ramona, had the disease just months after her birth. One night when Taylor kissed her child, she realized she had a very high fever and rushed her to the hospital. It took all day and many medical tests for doctors to determine the cause of Ramona's illness was sickle cell. The year was 1961. The swift detection helped doctors and Taylor do all they could to help treat the disease though she was gravely ill and they didn't know if she'd survive.

Taylor was trained by Dr. Robert Bigley and Dr. Robert Koler, two top geneticists at Oregon Health Science University to better her understanding of sickle cell and become an expert herself. She brought in top Hematologists, such as Dr. Elliot Vichinsky of Oakland Children's Hospital and another from Denver, holding seminars at community hospitals to promote and fos-

ter better treatment of the disease by enhancing critical knowledge.

Students were tested and families educated and informed after transforming her support group into a full blown organization; formally known as The Portland Sickle Cell Anemia Foundation,

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which is now the Sickle Cell Anemia Foundation of Oregon. From the foundation, she's been able to provide a plethora of resources to people impacted by the disease.

Despite her knowledge and continued medical care, Taylor's daughter continued to suffer gravely. At the age of 37, Ramona passed due to complications from sickle cell anemia.

Taylor's now adult granddaughter, TaNieshia Taylor, re-

members having to tend to her mother, even removing IV's from her ports and witnessing the symptoms become unmanageable. The fatigue weighed heavy and the pain excruciating. In spite of the trauma, TaNieshia says she is mostly thankful for the 16 loving

years that she had with her mother, being part of her care, and learning about the disease.

"I was lucky in a way with it already being known that my mom had it, but for a lot people they don't even know what warning signs to look for, and that's the problem," she says.

Patients can benefit from crucial early treatment. Tiffani Moss, a recent Portland transplant, became aware early on that she has

sickle cell anemia and has been able to get the medical care she needs. Because she has high fetal hemoglobin, she has had few painful episodes. Other victims of sickle cell can work and live somewhat normal lives.

Moss now works closely with The Sickle Cell Foundation of Oregon. At 34, she says her day-to-day activities go unhindered; she is even able to work 40 hours a week at a research facility despite carrying the full blown version of the disease. This is the other side of a rare coin.

The significance of knowing you have sickle cell goes beyond just personal health. Moss too is a mother. When she and her husband brought their child into the world recently, she made sure to have her tested immediately. The results were positive.

Knowing some of the statistics on passing on the sickle cell traits to an heir, she urged her husband to get tested. The Center for Disease Control reports that if both parents are carriers of the sickle cell trait, their children are 50 percent more likely to inherit the

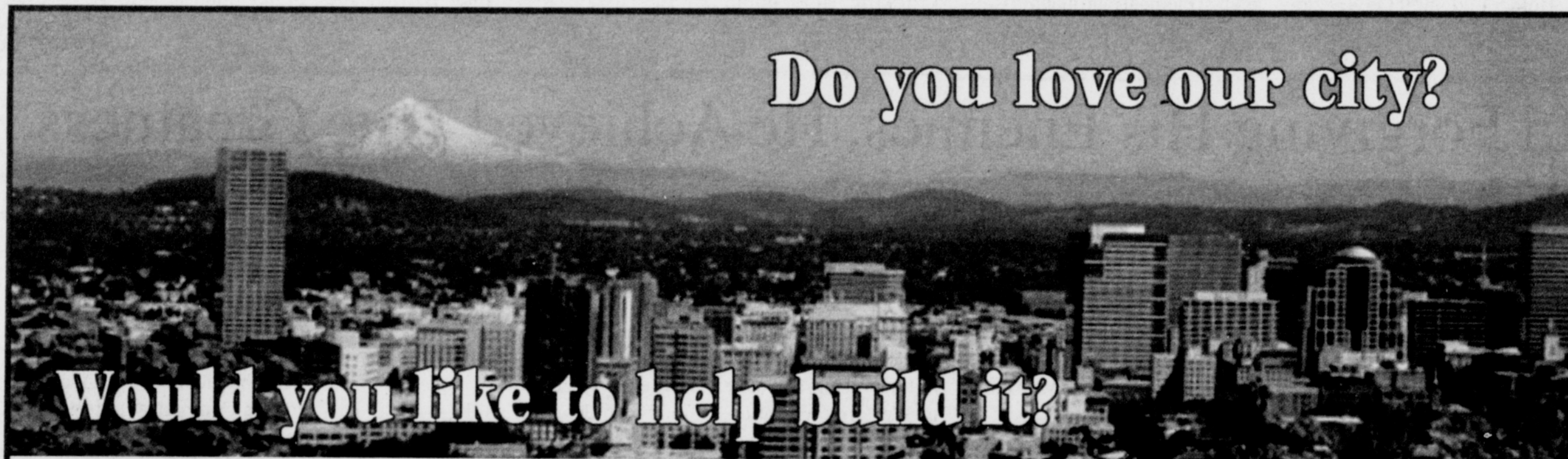
genes. He reluctantly got the test only to find out that he indeed possessed the sickle cell trait.

"If it weren't for our child, he could have gone on for years not knowing that he had the disease," Moss says.

September marks Sickle Cell Awareness Month. In honor of the annual observance, the Sickle Cell Anemia Foundation of Oregon is planning a 5K 'Buddy Walk-a-Thon' for Saturday, Sept. 28. The Portland walk comes as an effort to increase funding for the various resources the organization provides to local sickle cell patients and to raise the awareness level. The Foundation also hopes to increase the amount of members on its board of directors.

Taylor says with 1 in 12 African-American carrying the gene for this disease, she hopes churches and various organizations will help fund not only the walk-a-thon but the Foundation's long term programs as it continues to fight the cycle of sickle cell.

For more information about sickle cell and the walk, visit sicklecellanemiaportland.com.



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