The Sickle Cell Oregon Globe

Supporting Families ♦ Building Community ♦ Sharing Hope

Serving The Pacific Northwest & Hawaii

Sickle Cell Community Update

- This month: staying healthy in winter
- New CRISPR breakthrough offers hope
- Gene therapy access expanding in 2026
- Medicaid now covers gene therapies
- Cold weather safety tips inside
- New research identifies genetic targets

A Message from the Executive Director

Pastor Marcia Taylor, MA
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Staying Safe and Healthy This Winter

As we move through February, cold weather remains a significant concern for our sickle cell community. Cold temperatures cause blood vessels to narrow, particularly in the hands, feet, nose, and ears. For those living with sickle cell disease, this constriction can trigger painful crises. **Why Cold Weather Matters** When our bodies are exposed to cold, blood vessels narrow to preserve heat. For people with SCD, this makes it even harder for blood to flow properly, increasing the chance of a vaso-occlusive crisis. Acute pain crises or vaso-occlusive crisis are the most common clinical manifestation of SCD. A VOC occurs when sickled red blood cells irritate the lining of blood vessels and cause an inflammatory response leading to vascular occlusion, tissue ischemia and pain. Painful vaso-occlusive crisis (VOC) remains the most common reason for presenting to the Emergency Department and hospitalization in patients with sickle cell disease. **Protect Yourself This Season** The key is to stay warm and minimize exposure. Dress in layers so you can adjust to temperature changes. Keep your home warm, and if you must go outside, limit your time in the cold. Stay hydrated and make sure you've received your flu vaccination.

GIVE THE GIFT OF LIFE —DONATE BLOOD THIS FEBRUARY

Blood transfusions remain one of the most critical treatments for sickle cell patients. February, the month of love, is the perfect time to show care for those in need. Sickle cell patients benefit most from blood transfusions from donors of similar ethnic backgrounds, but only five percent of blood donors are of African ancestry. Help us make a difference for SCD patients by pledging to donate blood this month.

Winter Safety Tips for SCD

- Dress in warm layers
- Keep extremities covered
- Stay well hydrated
- Avoid prolonged cold exposure
- Keep your home warm
- Get your flu vaccination
- Don't skip daily medications
- Know the warning signs

Research & Treatment Updates

New CRISPR Breakthrough: Gene Therapy Without Cutting DNA

Scientists at UNSW Sydney have developed a groundbreaking new form of CRISPR technology that could make gene therapy safer for sickle cell disease patients. Published in January 2026 in Nature Communications, this research shows that genes can be reactivated without cutting DNA strands—potentially avoiding the cancer risks associated with traditional gene editing. Rather than cutting DNA, the new technique uses a modified CRISPR system to deliver enzymes that remove chemical "brakes" keeping certain genes switched off. One key target is the fetal globin gene, which helps deliver oxygen before birth. Reactivating this gene after birth could help bypass the defects that cause sickle cell disease. "Whenever you cut DNA, there's a risk of cancer," explains Professor Merlin Crossley. "But if we can do gene therapy that doesn't involve snipping DNA strands, then we avoid these potential pitfalls." This safer approach could open doors for treatments with fewer unintended side effects.

Gene Therapy Access Expands Through Medicaid

A new federal program is making life-changing gene therapies more accessible for sickle cell patients on Medicaid. The Cell and Gene Therapy (CGT) Access Model, which began in 2025, allows states to offer FDA-approved gene therapies through outcomes-based agreements with manufacturers. Two gene therapies—one costing $2.2 million and another $3.1 million per patient—are now available through this program. Early results are promising: patients like 18-year-old Serenity Cole from Missouri have experienced significant improvement after treatment. The program addresses a critical need: Medicaid covers roughly half of Americans with sickle cell disease.

Scientists Identify New Genetic Target for Treatment

Johns Hopkins Medicine researchers have identified a potential new gene target—FLT1—that could be edited to treat sickle cell disease. Published in March 2025 in Nature Communications, the research analyzed whole genomes of 3,751 people with sickle cell disease and identified 14 novel genetic markers related to fetal hemoglobin production. "With these new genetic markers, we now know 90% of the genes associated with fetal hemoglobin production in sickle cell disease patients of African ancestry," explains Dr. Ambroise Wonkam.

Stay Connected With SCAFO

For more information about our programs, support groups, and community events, visit us at **www.sicklecelloregon.org** or call **503-249-1366**. Follow us on social media for the latest updates and resources.