



The Sickle Cell Oregon Globe

Supporting Families | Building Community | Sharing Hope

Serving The Pacific Northwest & Hawaii

Headlines:

New Bone Marrow Treatment Shows Promise

Understanding Pregnancy and Sickle Cell Disease

Drug Safety Update

Support Group News

Stay Healthy This Fall!

Quick Tips for Pain Management

Breakthrough News:

New Bone Marrow Treatment Shows Promise

Exciting news from medical centers across the country! Doctors have found a new way to help cure sickle cell disease using a special type of bone marrow transplant.

This new treatment, tested at places like Johns Hopkins and Vanderbilt, has helped over 97% of adult patients. The best part? It uses donors who are only "half-matched" - like parents, brothers, or sisters - instead of needing a perfect match.

"Virtually everyone has a half-matched donor in their family," says Dr. Robert Brodsky from Johns Hopkins. This means more people can get help than ever before.

The treatment costs much less than gene therapy (about one-fifth the price) and has fewer side effects. While it's still being tested, this gives us real hope for more treatment options in the future.



Sickle Cell Support Group

Attention Sickle Cell Warriors:

Please join us Thursday night, ONLINE
October 17, 2025 7:00 PM - 8:00 PM
for our monthly support group meeting.

Learn. Share your stories. Meet others.
Receive support and resources!

We meet on the 3rd Thursday of the
month on Zoom:
<https://tinyurl.com/SCDZoom>

If you haven't joined us before, be sure to register
here: <https://tinyurl.com/scdgroup>



Contact us if you have questions or if we can be of
help in other ways — 503-249-1366

Understanding Pregnancy and Sickle Cell Disease

Great news for women thinking about having babies! The World Health Organization just released new guidelines to help pregnant women with sickle cell disease have safer pregnancies.

The guidelines remind doctors that women with sickle cell disease need special care during pregnancy. This includes:

- Extra folic acid and iron supplements
- More frequent check-ups
- Careful pain management
- Planning for delivery

If you're thinking about getting pregnant, talk to your doctor early. With good medical care, women with SCD can have healthy babies!

Staying Healthy This Fall

As the weather gets cooler, it's important to take extra care of yourself:

Stay Warm: Cold weather can trigger pain crises. Layer your clothes and avoid being outside too long in cold weather.

Get Your Flu Shot: People with sickle cell disease have a higher risk of getting sick from infections. Make sure you and your family get flu vaccines.

Drink Plenty of Water: Even when it's cold outside, your body still needs lots of water to stay healthy.

Take Your Medicine: Don't skip doses of hydroxyurea or other medications, even if you're feeling good.

Research You Should Know About

Scientists at Johns Hopkins found 14 new genetic markers that might help create better treatments. They studied over 3,700 people with sickle cell disease to find these new clues.

One exciting discovery is a gene called FLT1 that helps make fetal hemoglobin. This could lead to new treatments that help your body make more of the "good" hemoglobin.

This research shows that 90% of the genetic factors that affect fetal hemoglobin are now known. This knowledge helps scientists develop better treatments for more people.

Quick Tips for Pain Management

- Use heat pads on sore areas
- Try gentle stretching or walking
 - Drink warm liquids
 - Practice deep breathing
- Don't wait - call your doctor if pain gets worse

Important Drug Safety Update

If you take or have taken Oxbryta (voxelotor), you should know that the company Pfizer removed this medicine from the market in September 2024.

They found that the medicine might cause more health problems than it helps. If you were taking this medicine, make sure to work with your doctor to find a different treatment.