

A new treatment is restoring skin coloration to some with vitiligo

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Credit: Unsplash/CC0 Public Domain

Sarah Hayden owns a lot of turtlenecks. She also has chunky necklaces and tons of makeup—anything to cover up the blotchy white skin on her face, neck, hands and knees.

When she was about 23, Hayden was diagnosed with [vitiligo](#), a noncontagious skin condition that leads to the loss of pigmentation. It struck first on the back of her neck and then, as with many people, slowly progressed under her eyes and across her face, before jumping down to her knees, elbows and fingertips.

Once, when she stepped into a hot tub, a woman made a comment about how people with skin conditions shouldn't be in hot tubs and paraded herself and her daughter out. Hayden pretended it didn't matter. That she still felt beautiful on the inside.

It was only when she joined a clinical trial for an [experimental drug](#) and her vitiligo began to recede that she "realized that having the skin condition affected me more than I thought it did," said Hayden, now 41, of Hood River, Oregon.

The medicated [cream](#) she used as part of that trial, ruxolitinib, was approved by the Food and Drug Administration this summer. Late Wednesday, *The New England Journal of Medicine* published a study showing ruxolitinib cream is extremely effective in about one-third of patients who use it for at least six months.

What is vitiligo and its treatment?

Somewhere between half a percent and 2% of people worldwide have vitiligo, which is now understood to be an autoimmune disorder, where the immune system attacks the cells in the skin that provide pigment.

Famous people with vitiligo include Michael Jackson, model Winnie Harlow, actor and director Jon Hamm, comedian Steve Martin, commentator and comedian Joe Rogan, and NFL player-turned coach Karl Dunbar.

The condition can be particularly distressing for people with naturally dark skin because the light blotches stand out even more.

Only one treatment has previously been approved by the FDA and it removes more coloration, to avoid blotchiness, rather than restoring the skin's natural color as ruxolitinib cream can sometimes do.

Right now, many patients are treated with steroids, which don't work well, or given controlled phototherapy sessions, which can be hard to access for people who live far from a center that offers it, said Dr. David Rosmarin, a lead author on the new study.

How ruxolitinib works

The use of ruxolitinib cream reflects a new understanding of vitiligo, Rosmarin said. It works by tamping down an overactive immune response. "We are now better at modulating, rebalancing" that arm of the immune system, Rosmarin said.

About 30% of the 450 people who received active treatment as part of two studies saw a dramatic improvement in facial pigmentation after six months. Up to half did after a year of treatment, indicating that the cream became more potent over time. More than 80% of people in both trials were white and only 3% to 5% were Black or Asian.

Formulated as a cream ruxolitinib does not affect the whole body, so side effects are relatively minor, usually just some acne where the cream is used, Rosmarin said.

Ruxolitinib cream seems to work best on the head and neck, with hands and feet the hardest to repigment, Rosmarin said. It's not yet known whether someone can take ruxolitinib for a period of time and then stop, or whether vitiligo will return without constant dosing.

Commercial insurers and Medicare have been covering ruxolitinib cream, Rosmarin said, now that there's "broad agreement in the medical community that it is a medical not cosmetic condition and treatment should be covered." One tube of the cream costs about \$2,000 and can last anywhere from a few weeks to a few months, depending on how much skin needs to be covered.

The amount of time a patient had vitiligo didn't affect their likelihood of success.

People who had poliosis vitiligo, or a total loss of pigmentation leading to pure white hairs, did not improve on the drug, said Dr. Brett King, who was not directly involved in the study but consults for Incyte, the Delaware-based company that makes ruxolitinib cream and sells it under the brand name Opzelura.

Researchers are also developing other approaches to treating vitiligo for those who don't see much improvement with ruxolitinib cream, Rosmarin said.

The study and recent approval of ruxolitinib cream "sets a pathway for other treatments to hopefully move forward," he said. "This is just the start."

The origins of the new approach date to 2017 when King, an associate professor of dermatology at Yale University, decided to test a rheumatoid arthritis drug in a mouse that works in the same way as ruxolitinib. It seemed to help, so he gave it to a patient who had the condition "from nose to toes," he said. Her dramatic improvement "was our first clue" that his approach might work.

"When you have an observation, but in particular one anchored in science, not just in chance observation, it leads to paradigm shifts in how

we think about disease and treat disease," King said.

The success with ruxolitinib will encourage other drug companies to develop vitiligo treatments, he said.

Because it takes so long to see a benefit from ruxolitinib cream, it would be useful to find a way of distinguishing patients who will respond well from those who won't, Dr. Liv Eidsmo wrote in an editorial accompanying the new study.

Eidsmo, a dermatologist and researcher at Karolinska University Hospital in Sweden, also pointed out that it's not clear what will happen if patients stop using the cream and raised concerns about the lack of diversity among trial participants, who were largely white.

Still, she wrote, thanks to [ruxolitinib](#), "patients with vitiligo finally have the hope of efficient treatments."

'It gave me back something I lost'

Hayden is one of those lucky patients.

The cream has returned about 90% of the pigment to her face. Even her hands, considered the hardest to reach for the drug, have mostly cleared up.

"It gave me back something I lost," said Hayden, who was wearing a V-neck shirt and a thin gold necklace on a recent video call. On weekends, she no longer insists on wearing makeup before leaving the house.

An instructional coach in her town's school district, Hayden had almost no side effects from the cream and didn't find it a burden to spread on her face, chest and hands twice a day during the two-year trial. "It was

just part of my morning routine," she said, "and it was part of my bedtime routine after I brushed my teeth."

The treatment changed her relationship with the sun. Before, she would wear high SPF sunblock, a hat and long sleeves if she was in the sun for long periods. With vitiligo, she said "you are either normal or burnt," there was no such thing as a tan.

During the trial, she said, she was encouraged to get limited amounts of sun exposure to promote skin regeneration. "Now, I feel like when I'm in the sunlight, it's regenerative instead of harmful," she said. "I have to be careful, but it's not the same burden as it was."

Hayden said she's grateful to have been able to participate in the research to help others avoid some of the same challenges she's faced.

"That really kind of fueled my 'why' for engaging in the trial," she said. "Not just for my own hope and excitement—which it did 100% and I would do it again in a heartbeat—but also potentially having this available to other people living with vitiligo."

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