

# Trump calls it a COVID-19 fix. Now lupus patients can't get their drug

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Credit: CC0 Public Domain

Before Aisha Kelley headed to the pharmacy last week, she heard from a fellow lupus patient that she might have trouble getting her prescription filled.

Her medication, hydroxychloroquine, sold by the brand name Plaquenil, keeps her body from turning against her. It is considered the most important drug for [lupus patients](#), but now is also being investigated as a possible treatment for the new [coronavirus](#).

Before Plaquenil, Kelley's children had to help her shower and dress because the autoimmune disease made her legs wobbly like Jell-O.

Before Plaquenil, sitting on the sofa exhausted her.

Before Plaquenil, her thick, shiny hair fell out in clumps.

At the Price Chopper pharmacy in Mission, Kan., the pharmacist told her she could only have a 10-day supply, not her usual 30-day.

"Well, do you know when you're going to get it?" Kelley asked him.

He couldn't tell her.

Pharmacies across the country have run out of the medication used by millions of lupus and rheumatoid arthritis patients, a drug many of them have taken daily for years.

Hydroxychloroquine started selling out after President Donald Trump touted it as a possible "game changer" treatment for the coronavirus. A French study released this month suggested that the drug, along with the antibiotic azithromycin, could be effective in treating COVID-19 patients.

Now supplies have dried up. And some patients are considering rationing their daily dosages, or skipping some days altogether, as health advocates and physicians caution them not to panic.

"My fear is I will be put in the hospital, and I don't want to go into the hospital," said Misty Helm, a 48-year-old lupus patient in Lexington, Mo.

She was diagnosed in 2004 after years of trying to keep weight on her body and watching her hands and feet swell up like sausages as she worked 22 years in the automotive industry, including a decade at Ford's Claycomo plant in Kansas City.

"It's not a fun disease," she said.

Reports have surfaced that people are stockpiling the drug. Now Missouri pharmacy officials have cautioned health care providers to stop prescribing the drug for a use it's not approved for.

Pharmacy boards across the country have reported that doctors are hoarding the drugs by writing prescriptions for themselves and family members, The Associated Press reported.

Several states, including Kentucky, Ohio, Nevada, Texas, and now Missouri, have issued restrictions or guidelines on how the drugs should be prescribed.

"Prescribing hydroxychloroquine, chloroquine and azithromycin for family, friends and co-workers in anticipation of a COVID-19 related illness can significantly impact drug supplies and may lead to improper use," said a joint statement last week from the Missouri State Board of Registration for the Healing Arts, and the Missouri Board of Pharmacy.

Because people scooped it up to use for coronavirus, Kelley now has enough of the little white pills—including ones she hasn't taken yet from her last refill—to last her for about two weeks.

"I'm nervous. I'm not going to lie," Kelley said.

Last week the Lupus Foundation of America, American College of Rheumatology, American Academy of Dermatology, and the Arthritis Foundation urged the White House task force and governors across the country to step in.

The Food and Drug Administration has approved hydroxychloroquine and chloroquine only for treating lupus, rheumatoid arthritis and malaria, the groups said in a joint statement, which noted their support for "rigorous clinical trials" to investigate the drugs for COVID-19 use.

"Already today, many of our patients are not able to fill their prescriptions, due to major shortages of hydroxychloroquine, with validated reports across the country of pharmacies having depleted their supplies and half of the drugs' manufacturers reporting back orders," they wrote.

After the French study came out, "we called around to our regional pharmacies and every pharmacy had several hundred tablets of Plaquenil available," said Alfred Kim, a rheumatologist and director of the Lupus Clinic at Washington University in St. Louis.

"But the issue then came afterwards, where social media, even state leaders, have made hydroxychloroquine ... have called it a cure. This obviously skyrocketed interest in Plaquenil."

Based upon limited anecdotal data, both hydroxychloroquine and chloroquine are being used to treat hospitalized coronavirus patients around the world, including the United States, according to the Centers for Disease Control and Prevention.

And though it has not approved the drugs specifically to treat

COVID-19, the FDA quickly approved clinical trials underway in Minnesota and New York.

Trump tweeted on March 22: "HYDROXYCHLOROQUINE & AZITHROMYCIN, taken together, have a real chance to be one of the biggest game changers in the history of medicine. The FDA has moved mountains—Thank You! Hopefully they will BOTH (H works better with A, International Journal of Antimicrobial Agents) ... be put in use IMMEDIATELY. PEOPLE ARE DYING, MOVE FAST, and GOD BLESS EVERYONE!"

"We saw it blow up over the weekend because President Trump keeps talking about it," said Amy Ondr, president of the Heartland Chapter of the Lupus Foundation of America, which covers Missouri and eastern Kansas.

"It's being prescribed off-label, and it shouldn't be. There is no approved use for this for COVID-19, though some physicians are still prescribing it to patients. We're getting a lot of questions like 'what if we run out?' We don't give medical advice."

But she does know what can happen to lupus patients who don't use their medication. It's called a lupus flair, "where their disease activity goes up," Ondr said. "That's when you can get damage to organs.

"Plaquenil kind of helps maintain their disease, so that is their fear, that if they go off the drug or they have to start cutting back on the dosage that they'll go into a lupus flair which potentially could be life-threatening for them."

Kim said stock has now "dwindled near zero and the supply chain hasn't quite caught up yet."

You can't get Plaquenil without a prescription. "It's definitely physicians and other health care providers, such as dentists, that are prescribing this," he said. "And there have been reports, which I have been able to confirm, unfortunately, of several prescribers who have been hoarding it.

"In my view this is an unethical use of the powers that they have to be able to leverage prescription medicines to treat certain diseases. Here in this specific case, the data is so weak that justification to treat COVID-19 patients is poor.

"But on top of that, there's absolutely no data whatsoever that supports its use as a preventative. So that's what people are using it for, as a preventative ... overinterpreting results that are already compromised due to study design issues."

The four health advocacy groups asked the government to work with the pharmaceutical industry to ramp up production and make 90-day supplies available on an ongoing basis to patients using the drugs for their approved use.

Kim said several drugmakers have already said they are going to make more. His clinic has put in a request to Novartis, which announced it is donating up to 130 million doses of generic hydroxychloroquine for use in clinical trials for treating COVID-19.

"We don't want to come across also as sounding like we don't want this drug to go to people with COVID-19. Of course we do," said Ondr. "We just want to have a little bit of responsibility here of what's happening."

Helm said as soon as she got an email from the Lupus Foundation warning her about the shortage she called her pharmacy in Lexington, but it was too late. They told her they didn't have any more Plaquenil and couldn't tell her when they would get more.



Helm said this has never happened before.

"It's frustrating because they had to know this was going to cause a shortage and that other people who are taking it were going to be affected," she said.

Her phone had been ringing so much all week that La Tanya Pitts-Lipprand of Kansas City did something she never does.

"Normally I don't get on Facebook like this. However, the last couple of days I've been getting a lot of calls concerning the announcement they're going to be using, in some cases, Plaquenil, for the virus," she said in a video she posted on the Facebook page of Marlene's Kaleidoscope, a lupus nonprofit she started in 2017.

Pitts-Lapprand, who is 52, was diagnosed with lupus nearly 30 years ago. When she went to CVS to get her usual three-month supply of Plaquenil a couple weekends ago, the pharmacist limited her to just one month because there wasn't enough.

In the video she talked about taking [phone calls](#) from fearful patients, "worried about not being able to get their medicine at this time. I want everybody to understand, we will get through this.

"Today I got four calls about people with their fears and concerns and they're talking about rationing out their medicine, like take it today but not take it tomorrow or cut it in half, or hold onto it until they feel sick and then have to take it.

"I am not a doctor. I am somebody who has been having lupus for over 27 years. And I personally don't think that's a good idea."

Ondr has gotten the same calls.

"This is a drug that very many lupus patients are on, sometimes it's first-line drug for people who are diagnosed with lupus. So they've been on it for a long time," said Ondr. "They're panicking. They're running out. The pharmacies don't have it."

Kim is trying to tamp down the panic among his patients, reassuring them that more is on the way.

He's also telling them to try mail-order outlets, which might have more stock. One company, Express Scripts, "has done a great job of trying to shore up supplies," he said.

The caveat: That advice is based on information that changes nearly every day. "The situation is so dynamic and changing," he said.

"So right now, I think the best thing (for patients) to do is to continue taking the medicine until they run out. Be in communication with their prescriber, usually their rheumatologist, to get a better understanding of the lay of the land."

In the meantime, Pitts-Lipprand has launched a one-woman campaign, knowing that stress is not good for anyone living with lupus. Given stay-at-home orders in the Kansas City area right now, she can't meet one-on-one with anyone right now. But she'll be back soon on Facebook.

"I want everyone to calm down," she said.

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