

# There's a black market on social media for pricey fertility drugs

December 18 2023, by Kristen V. Brown, Bloomberg News

---



Credit: CC0 Public Domain

After in vitro fertilization led to a miscarriage, Lindsay found herself with thousands of dollars' worth of fertility drugs she could no longer

use.

She was lucky: Insurance covered most of her costs. But for the majority of people, fertility care is not covered. So Lindsay didn't want to waste her drugs.

"I knew people were paying a lot for these," she said. "It seemed sort of criminal to throw them away."

Lindsay and the other women living in the U.S. interviewed for this article asked that only their first names be used because it's against federal law to possess or consume drugs not prescribed to you.

Lindsay looked for fellow fertility patients who might want her medications. She found them on social media. On Instagram, patients used hashtags to covertly signal they had fertility drugs for offer, or that they were in need. On Facebook, Listservs and Discord groups, people swapped (and sometimes sold) leftover medications.

As more women postpone having children until later in life, infertility has become a growing problem, with the World Health Organization estimating that about one in six people globally are now impacted. The global fertility market was worth about \$35.2 billion last year and is expected to grow to \$84 billion by 2028, according to market research firm Imarc.

In the U.S., procedures like IVF and egg freezing have steadily risen each year save for a dip during the COVID lockdowns of 2020. Procedures rose more than 26% in 2021, the most recent year available.

Infertility treatments can be expensive. According to the American Society for Reproductive Medicine, one round of IVF treatments averages more than \$12,000 in the U.S. Medications alone can easily top

\$5,000. Yet only 43% of large U.S. employers offered IVF coverage in 2022 and most states do not require [private insurers](#) to offer fertility benefits.

It's a quirk of fertility care that patients often wind up with leftover drugs. Treatments that ramp up egg production and prepare the body for pregnancy typically come via mail from special-order pharmacies. Doctors generally prescribe more than will likely be required so doses can be adjusted. Those patients who respond especially well to medication can easily wind up with twice as many drugs as they need.

When Lindsay, who was 37 when she started IVF, miscarried six and a half weeks into her pregnancy, she still had enough drugs to last at least another month. Through the course of three rounds of IVF, Lindsay estimates she shipped drugs to around 20 other women. Some required refrigeration, so she overnighted them in coolers. Occasionally she would include a small token, like candies or socks with pineapples, the unofficial symbol of IVF.

Laws forbidding the sharing of prescription drugs aren't likely to be enforced when the medicines aren't considered potentially abusive, said Hank Greely, a law professor at Stanford University. The U.S. Drug Enforcement Administration says fertility drugs, which are not considered controlled substances, do not fall under its purview.

There are, of course, inherent risks in buying drugs from strangers on the internet.

"You don't know if the drugs were stored properly or that they are legitimate," said Art Caplan, a bioethicist at New York University's Grossman School of Medicine.

This warning was echoed by the U.S. Food and Drug Administration.

Treatments received outside the legitimate supply chain could "contain the wrong ingredients, contain too little, too much or no [active ingredient](#) at all, or contain other harmful ingredients, or otherwise be unsafe," a spokesperson said.

Another patient, Hollee, underwent IVF after losing her fallopian tubes to cancer. Without fertility coverage, she and her husband were looking at about \$30,000 in medical expenses, plus another \$12,000 for prescriptions. She joined an IVF support group on Facebook where patients commonly sell and give away unneeded medications. One woman offered to sell two types of drugs for \$680—a bargain. But the drugs never came.

Many IVF groups carefully screen members to weed out scammers by requiring identification and proof that a person is undergoing fertility treatment. Some groups forbid the trade of drugs altogether; a moderator of one group told Bloomberg that scams are just too common. Eventually, Hollee, 37, and her husband bought medications from another group member. All in all, they spent about \$3,500, still a fraction of the pharmacy cost.

"We still saved even though we got scammed," said Hollee. "If we want to do IVF, we're forced to do it this way."

Certain fertility drugs require refrigeration to remain potent. Drugs that have been mishandled or are too old carry the risk of not working—jeopardizing the success of an expensive and often emotionally grueling IVF cycle.

Rachel, 33, said her doctor advised her that medications were generally fine for six months after the expiration date. (She and other patients take the black market drugs under the supervision of their doctors.) Rachel makes sure drugs she purchases on Facebook are still in their original

packaging and sealed. She and other patients still take the black market drugs under the supervision of their doctors.

"It is a little scary when you're taking any medication from a stranger," she said.

She had taken a second job bartending to help pay for fertility treatments, but by sourcing drugs on Facebook, she was able to avoid taking out a loan. Many women interviewed said that strangers donating or selling deeply discounted drugs online are a lifeline.

"It's like a sisterhood that nobody wants to be part of, but you want to help everyone that's in it," said Beth, 48, who received donated medications through an email Listserv of patients at her clinic, then donated drugs herself when she and her husband decided to adopt a child.

Drugmaker EMD Serono, which makes fertility drugs including Gonal-f, said that it is aware of the trading practices and "advises patients to always obtain medications only from licensed distributors and pharmacies." The company also suggested patients inspect packaging for evidence of tampering and advised against using expired products.

Insurers Aetna and UnitedHealth declined to comment on selling and donating [fertility drugs](#). Other insurers didn't respond to requests for comment.

Meta Platforms Inc., which operates both Facebook and Instagram, referred Bloomberg to its policies on restricted goods, which prohibit individual sale or donation of prescription drugs.

Resolve, the national infertility association, warned in a statement that sharing unused medication "can come with a myriad of risks," adding "If

you're unsure of what to do with your leftover medications, it's best to consult with your infertility practice to understand the local laws."

Some clinics do informally support such practices. Beth, for example, said her clinic turned a blind eye to patients leaving leftovers in a coat closet. It's hard for clinics and doctors to officially endorse the practice, though, because they have no way to assess the legitimacy or quality of the drugs.

"I understand why it happens, but I can't advocate for it," said Zev Williams, director of Columbia University Fertility Center.

Sometimes, he said, when patients are cost conscious, his group will start out prescribing smaller amounts of drugs, and order more if needed. Yet usually patients wind up with excess drugs, he said.

Caplan, the NYU bioethicist, said fertility doctors should discuss ways to legitimize leftovers.

"That doesn't happen," he said. "I think this area needs more attention."

After Lindsay ending up moving and no longer had the insurance coverage she needed for IVF treatment, she wound up tapping the underground fertility market for donated drugs herself. Eventually she did get pregnant, and gave birth to a son, and later a daughter.

2023 Bloomberg News. Distributed by Tribune Content Agency, LLC.

Citation: There's a black market on social media for pricey fertility drugs (2023, December 18) retrieved 9 May 2024 from

<https://medicalxpress.com/news/2023-12-black-social-media-pricey-fertility.html>

|   |
|---|
| This document is subject to copyright. Apart from any fair dealing for the purpose of private |
|---|

study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.