

Here's why, and how a new drug might change how doctors treat peanut allergies

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Lauren Tilmont didn't believe it when her doctor told her a few years ago that he had a treatment that might allow her to eat peanuts, despite a lifelong allergy to them.

"The first thing I told him was, "You're crazy. That doesn't happen," " said Tilmont, 25, of Rogers Park.

She had been told nearly her whole life that peanuts could kill her. She lived in fear of them. But Tilmont decided to give her doctor's treatment plan a try.

He gave her a tiny bit of [peanut](#) protein and monitored her in his office for allergic reactions. Gradually, he stepped up the amount she ate, over the course of about 10 months. Today, peanut butter still upsets her stomach, but she can snack on Snickers bars and munch on peanut M&Ms without a problem.

Tilmont called the treatment the most difficult thing she's ever done, but she no longer fears accidentally touching a surface that has peanuts on it or eating at restaurants that use peanut oil.

"It has empowered me," she said.

It's a somewhat controversial treatment that hasn't been widely available in the Chicago area or elsewhere, despite high demand. But a similar approach may be about to go mainstream.

Earlier this month, a U.S. Food and Drug Administration expert panel recommended approval of the first drug designed to reduce allergic reactions in children with peanut allergies. The recommendation makes it likely that the drug, Palforzia, made by Aimmune Therapeutics, will get FDA approval.

The drug is not meant as a cure or a path to snacking on peanuts. Rather, it's designed to decrease the amount and severity of allergic reactions after accidental exposure to peanuts. But many families dealing with peanut allergies say it could be life-changing, potentially freeing them

from the worry that their kids could go into anaphylaxis or even die because of a simple mistake or oversight.

Doctors and patients who've used a somewhat similar treatment for years agree that the drug has the potential to help more people avoid deadly allergic reactions. But they also warn that the process may not be right for everyone and isn't as easy as it might seem at first blush.

"We are glad this is coming to the forefront, but it is not for all patients," said Dr. Paul Detjen, the Kenilworth physician who treated Tilmont, of the new drug.

Palforzia delivers a daily dose of peanut protein that's gradually increased over time, for children ages 4 to 17. After about a year of taking the drug, about two-thirds of children in a clinical trial were able to eat the equivalent of at least two peanuts without an allergic reaction, according to a study published last year in the *New England Journal of Medicine*.

Nearly one-third of kids who took the drug for a year still experienced moderate or severe symptoms when they ate peanuts. Also, children who took the drug suffered more [allergic reactions](#) during the treatment period than those who took a placebo.

Detjen, and more than 100 other private practice doctors across the country, have been performing somewhat similar treatments for years. Both the drug and the doctors' treatments are considered oral immunotherapy—though such therapy for peanut allergies isn't widely recommended. Currently, the standard of care for food allergies is not to treat the allergy itself but rather to avoid the allergy-causing food and always carry a supply of injectable epinephrine, such as an EpiPen, to counter reactions.

In the Chicago area, only a handful of doctors offer oral immunotherapy, though many parents want it for their kids. Some of Detjen's patients travel from Wisconsin and Indiana to see him.

Once a week, Caroline Bui and her 11-year-old son Mathieu Bui drive about an hour from their South Loop home to Detjen's office in Kenilworth.

Mathieu is late to school on those days, but his mom said it's worth it to ensure his safety in a world filled with foods that previously might have harmed him.

Mathieu started oral immunotherapy for his peanut allergy in April of last year. He started by taking the equivalent of a one-hundred-thousandth of a peanut, in the form of powder mixed into a drink, in Detjen's office, and then was monitored for a reaction. He took that same dose for a week before returning to the doctor to increase the amount, again being monitored for signs of an allergic reaction.

He repeated that process weekly for about seven months until he was finally able to eat a full serving—24 whole peanuts without an allergic reaction. He now eats five peanuts each morning to maintain his desensitization to the food.

"I couldn't eat a lot of foods," the sixth grader said. "It's a big difference."

His mother called the treatment "life-changing." Mathieu has recently had a string of firsts: first milkshake, first Chinese restaurant, first donut.

"You really don't have to worry about this kind of stuff anymore," Caroline Bui said. "The fear is gone."

Mathieu is going through the process again, this time to address his allergy to tree nuts.

Recently, he sat in an exam room in Detjen's office in front of small cups of cashew milk and walnut milk, flavored with chocolate syrup. Slowly, he drained each cup with a straw and then sat with his mom in the room for 45 minutes, with doctors and nurses occasionally peeking in to make sure he wasn't having a reaction.

When the timer beeped, he grabbed his backpack, ready for the drive back to the city with his mom.

Despite those kinds of results, doctors and patients warn that oral immunotherapy is no panacea.

Both Detjen and Dr. Sakina Bajowala, a North Aurora doctor who also offers the therapy, tell patients to eat food before taking their doses and ask them not to exercise for about two hours afterward. If the process is successful, patients may have to agree to eat peanuts every day for years, even if they don't like the taste. It takes a tremendous amount of discipline, planning and commitment, both from children and parents.

The doctors also warn that side effects and reactions may still happen, including at home where it will be up to parents to take action.

Some patients, for example, have stomach aches, nausea or vomiting while undergoing the therapy. Some can develop a condition in which the esophagus becomes inflamed, causing trouble swallowing.

"This is definitely not a therapy you want to take lightly or take willy-nilly," said Bajowala, who's been offering it at her practice since 2011.

The treatment puts demands on doctors and their staffs too.

Part of the reason so few doctors offer it may be because it's not something for which they can bill insurance, Bajowala said. Some doctors bill insurers just for the time they spend with patients and then charge patients for the costs of making the peanut protein or an overall fee for the process. Those patient costs can range from a couple hundred dollars to thousands of dollars.

Some doctors worry about the potential risks to patients. Still others may not have offices that can handle patient calls at all times of the day.

"You can imagine as the parent of a child with life-threatening allergies who's being asked to feed this to your child at home, some question may happen at 1 a.m., some may happen at 2 p.m. on a Sunday," Bajowala said. "You need to have that open level of communication."

Because so few doctors offer the treatment, their wait lists tend to be long.

That's where doctors and patients say the new drug, if approved by the FDA, may help. Researchers also have been studying whether people with peanut allergies can be desensitized through drops placed under the tongue, and one company has developed a patch for the skin, but neither of those approaches is as close to getting FDA approval as Palforzia.

The agency is expected to decide by January whether to approve the drug.

Palforzia "would open up the opportunity for all allergists to be able to offer some treatment to their patients that has been protocol-driven and gone through (clinical) trials," said Dr. Ruchi Gupta, a professor of pediatrics at Northwestern University's Feinberg School of Medicine who studies food allergies. "It gives them a little more confidence to offer it."

Gupta, who also is a pediatrician at Lurie Children's Hospital, noted that questions still remain about the drug.

It's unknown what the treatment would mean for patients long-term or if they'll need to take the medication for the rest of their lives. Long-term usage could be a pricey. Jayson Dallas, CEO of Aimmune Therapeutics, said in a statement that the company won't set a price for Palforzia until after the FDA's decision. But analysts have said it could cost about \$4,200 a year.

In July, the Institute for Clinical and Economic Review, an independent, nonprofit research institute, said evidence was inadequate to show that either Palforzia or the patch were better for a person's health than just avoiding peanuts altogether.

In addition to the financial commitment, there is the commitment a family must make to a very structured treatment plan.

"It needs to be taken seriously as an undertaking by a family," said Dr. Rachel Glick Robison, an attending physician at Lurie who helped lead a clinical trial of Palforzia at Lurie. "It's not something they can just add in easily to their routine."

Patients who've already undergone the therapies offered by private practice doctors can attest to that.

Amy Williams, who lives in the north suburbs, said her daughter, now 9, had some tough days while she was being treated for her peanut allergy. It was hard to wake up early every morning and force down breakfast and then nuts. But she said her daughter was determined.

Before the treatment, her daughter had anxiety about food. The family avoided restaurants and sometimes even birthday parties so her daughter

wouldn't feel excluded when it came time to eat cake.

The therapy has changed all that, she said.

"She goes into social situations with so much more confidence," Williams said. "Now she doesn't have to worry about what she's eating. She can just have fun and worry about stuff 9-year-olds worry about."

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